ITCH 96: Appropriate Systems/Appropriate Decisions: A Conference Addressing Information Technology Issues in Community Health

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APPROPRIATE SYSTEMS/
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A Conference Addressing
Information Technology Issues
In Community Health

PROCEEDINGS

November 3 - 6, 1996
Victoria Conference Centre
Victoria, BC, Canada

Sponsored by

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ITCH '96
APPROPRIATE SYSTEMS/APPROPRIATE DECISIONS

Proceedings of the Sixth National and Fourth International Conference on Information Technology and Community Health

Victoria Conference Centre
Victoria, BC, Canada
November 3 - 6, 1996

Sponsored By:
School of Health Information Science
University of Victoria
British Columbia Ministry of Health and Ministry Responsible for Seniors
Canadian Public Health Association
Canada's Health Informatics Association (COACH)

Edited By
Lawrence R. Scott
ITCH '96 Organizing Committee

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- RISE Healthcare
- School of Health Information Science, University of Victoria
As Minister of Health and Minister Responsible for Seniors, it gives me great pleasure on behalf of British Columbia to welcome you to Victoria for the 1996 Information Technology in Community Health Conference - ITCH'96.

A special welcome is extended to those visiting us for the first time from across Canada and around the world. I understand that the Conference will include delegates from such places as the USA, France, Austria, South Africa, Germany, England, Sweden and Australia. I hope all of our visitors enjoy their stay and will have the opportunity to explore some of the many scenic attractions the Victoria area has to offer.

The Conference theme, Appropriate Systems/Appropriate Decisions and the deliberations that will arise from it are very much in keeping with the Ministry of Health’s commitment to more effective management of the information needed to support a changing health system. It is clear that consistent and accurate information is critical to the success of providing appropriate services which improve health outcomes. The focus on information technology issues in community health support the movement of these services closer to home allowing for consideration of the needs of individual people.

The ability to more effectively and efficiently manage the health system, increase the emphasis on the continuum of care and in improving community health can all be helped with better information. This Conference provides an important forum for sharing knowledge and experience.

I wish you every success in your deliberations.

Sincerely,

Joy K. MacPhail
Minister

Province of
British Columbia

Minister of Health and
Minister Responsible
for Seniors

Parliament Buildings
Victoria, British Columbia
V8V 1X4
GREETINGS FROM THE CITY OF VICTORIA!

It gives me great pleasure on behalf of my colleagues on Council and the citizens of Victoria to send Greetings to the ITCH '96 Conference. I understand delegates are coming locally and from across Canada, England, Australia and India. I’m sure the conference will give all of you ample opportunity to discuss “Appropriate Systems/Appropriate Decisions”.

Victoria is a beautiful location to hold a conference. I hope our weather meets your approval! In addition to attending ITCH '96 Conference, I hope you will enjoy the many sights and sounds Victoria has to offer. In 1995 Victoria was voted the Best City in the World for Environment/Ambience by Conde Nast Traveler magazine in their 8th annual Readers’ Choice Awards. We are extremely proud of this distinction. First time visitors often comment on our breathtaking seascapes, views of the Olympic mountains across the strait, picturesque streets and unique 'olde town' buildings, not to mention our world renowned flowers and gardens. Victoria is a heritage city, not only rich in well preserved buildings but rich in culture, the performing arts and a variety of sports, including our world-class golf courses. You now have an opportunity to join the Conde Nast readers' opinion and experience for yourself the scenery, hospitality and friendliness of our community.

There is always a great deal of coordination in organizing an event of this size. I know that the Conference Organizing Committee has worked to coordinate ITCH, for which I commend them. In particular, my thanks to the UVIC School of Health Information Services and the Ministry of Health.

In closing, I hope you enjoy Victoria and your Conference. I wish each one of you success in the future.

Sincerely,

Bob Cross
MAYOR
**ITCH '96 - Table of Contents**

**Keynote Speakers**

Community Health in the New Century................................................................. 1  
*J. Gerrard*

Information Systems Development and Health Sector Reform.............................. 2  
*R. Rodrigues*

How to Get Patients Discharged Before They Get Admitted.................................... 8  
*J. Fulton*

Clinical Encounter and Data Capture in a Busy Family Practice Environment........... 9  
*D. A. Wade*

The Importance of an Information Management and Technology Strategy................ 11  
*R. Rogers*

**Student Poster Contest Submissions**

The Quality of Dietary Information on the World Wide Web................................. 15  
*K. Davidson*

Continuity of Care Patient Profile......................................................................... 19  
*P. Flanagan*

A Bottom-up, Concept Based Methodology for Indexing and Searching MEDLINE........ 22  
*M. H. Miller*

A Methodology for Defining a Data Set for a Computer-Based Patient Record............ 28  
*R. W. Padgham*

Self-Help by Electronic Mail: Perceptions and Meanings of Computer-Mediated Support Communities.... 34  
*J. C. Polzer, H. A. Skinner, B. D. Poland*

**Internet Applications - 1**

Canadian Community Health Centres and the Internet: Exploring the Challenges and Solutions.......... 42  
*R. Jamieson*

Is There a Telehealth Industry in Canada?.............................................................. 48  
*J. Picot*

Health in Action: A Flagship Project...................................................................... 54  
*C. Lowe, K. Belton, S. McMillan, J. Aspden, and P. Hodges*
Community Health Information Systems -1

Enhancing Community Development Through a Collaborative Community Profile Database ..................60
E. F. Harris and E. E. Dufresne

Moving from Hospital to Community: Impact of Patient Care Information Systems on the Delivery of Health Care Services .................................................................64
M. A. Hebert

Evaluating Primary Health Care Software Packages ...........................................................................70
T. McDonald

The BC Health Information Standards Council ..................................................................................76
J. H. Coward

Internet Applications - 2

Health Data Networks: The Central West Health Planning Information Network .........................85
G. Webster, J. Heale and T. Abernathy

Health Data Networks: The Central West Health Planning Information Network .........................85
G. Webster, J. Heale and T. Abernathy

A Homepage on the Internet for the Vancouver Island Cancer Centre ...........................................89
J. Barnett, M. Fedoruk, M. Gaucher and S. Larsson

Videophones for Medical Consultations .........................................................................................92
S. Chowdhury and J. Persson

Community Health Information Systems - 2

Minimum Data Set for the Community Rehabilitation Program in Alberta ........................................98
S. A. Strong

The Development of a Conceptual Design for a System to Support the Information Needs of the Long Term Care Program .................................................................105
J. Grant, P. Fisher and S. Frizzell

A Community Health Information System for the Emergency Department ................................112
B. D. Hoshstrasser, G. A. Reece, E. N. Barthell and S. K. Kulick

Considerations in the Implementation of a Child Health Record Information System .....................118
T. Halbert and D. Martin

Internet Applications - 3

Information Superhighway or Information Traffic Jam for Health Care Consumers? .......................124
I. McGrath

Information Technology (IT) Infrastructure for Regional Laboratory Services ..............................129
H.D. Covvey and J.W. Steiner
<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowering Physician Hospital Resource Consumption Using Low-Cost Low-Technology Computing</td>
<td>136</td>
</tr>
<tr>
<td>C. C. Johnson and M. Martin</td>
<td></td>
</tr>
</tbody>
</table>

**Community Health Information Systems - 3**

<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Client Information System for a Community Oriented, Multi-Faceted, Pediatrics Health Care Centre</td>
<td>145</td>
</tr>
<tr>
<td>R. Johnstone, D. Wattling and H. Schmidt</td>
<td></td>
</tr>
<tr>
<td>The Community Equity Model of Health Care: Framework, Theory, Technology, and Data</td>
<td>152</td>
</tr>
<tr>
<td>D. E. Ford and L. Pentland</td>
<td></td>
</tr>
<tr>
<td>Dealing with Information Accessibility and Security</td>
<td>164</td>
</tr>
<tr>
<td>S. Lafrance</td>
<td></td>
</tr>
<tr>
<td>Heart Health Information System; A Tool for Project Management</td>
<td>169</td>
</tr>
<tr>
<td>L.E. Blaire, J.M. Yelland Demooy, P.J. Naylor, L.W. Green, J. Frankish, H. MacLeod Williams, B. O'Connor</td>
<td></td>
</tr>
</tbody>
</table>

**Emerging Needs and Technologies**

<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>“TeenNet”: Using The Internet to Engage Teens in Health Promotion</td>
<td>178</td>
</tr>
<tr>
<td>H.A. Skinner, K. L. Bercovitz, M. M. Morrison and J. Polzer</td>
<td></td>
</tr>
<tr>
<td>Building a Health Information Network: What Information for What Purposes</td>
<td>181</td>
</tr>
<tr>
<td>T. Abernathy, J. Heale and G. Webster</td>
<td></td>
</tr>
<tr>
<td>Community Health Information Systems: Continuing Care Data Warehouse Project “Doing more with what you have!”</td>
<td>185</td>
</tr>
<tr>
<td>P. J. Andru and P. J. Gillan</td>
<td></td>
</tr>
<tr>
<td>DIABCARD - A Smart Card for Patients with Chronic Diseases</td>
<td>193</td>
</tr>
<tr>
<td>R. Engelbrecht and C. Hildebrand</td>
<td></td>
</tr>
</tbody>
</table>

**Supporting Physician Needs**

<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Practice Guidelines and Decision Support Technologies: Assets and Liabilities in Common</td>
<td>200</td>
</tr>
<tr>
<td>W. Farnsworth and P. J. Mariani</td>
<td></td>
</tr>
<tr>
<td>The Development of a Research Database to Enhance Autonomy and Evidence-based Practice in Public Health: The Public Health Effectiveness Project</td>
<td>211</td>
</tr>
<tr>
<td>M. Dobbins, S. Hayward, D. Ciliska and G. Brunton, H. Thomas, J. Underwood</td>
<td></td>
</tr>
<tr>
<td>Casemix Simulation Modeling in the Healthcare Industry</td>
<td>214</td>
</tr>
<tr>
<td>M. Mahendran, J. Palmer, J. Dowling and M. Quaddus</td>
<td></td>
</tr>
</tbody>
</table>
Public Education Approaches

Automatic Customization of Health-Education Brochures for Individual Patients .......................................................... 222
G. Hirst and C. DiMarco

The Public Health Effectiveness Project: An Overview ...................................................... 229
M. Dobbins, D. Ciliska, S. Hayward, H. Thomas, J. Ploeg, G. Brunton and J. Underwood

A Community Health Information Model: An Information Management Approach to Information Systems Development ........................................ 233
J. Bargenquast

From Regional Planning to Information Systems Design (The Lupus HealthNet Experience) ................................. 238

Physician Resource Systems

Application of Clinical Workstations: Functionality and Usability ............................................................. 242
S. Graeber

The Office of the Future Project: The Integration of New Technology Into Office Practice: Academic Detailing Through the Super Highway ....................................................... 249
R.M. Tamblyn, A. Jacques, R. Laprise, A. Huang, R. Perreault

Physician Resource Data Bases: An Essential Tool for Planning ........................................................... 252
L. Buske and S. Newton

National and Provincial Strategies

Health Information Management Project .................................................................................. 260
J. Karim

Mental Health Applications

Strategies To Meet The Health Information Needs of People With Intellectual Disabilities .................................. 268
D. Bradley and N. Cuthbertson

Health Status Determination

Harmonisation of Regional Health Data Requirements in the South Pacific ................................................. 274
L. Sauve and Y. Souares

MONI: Monitoring of Nosocomial Infections ................................................................. 281
C. Chizzati-Bonfadin, KP Adlassnig, W. Koller and M. L. Rotter
Using Health Indicators to Assess Aboriginal Health in Manitoba ............................................................. 286
C. Green, L. Poffenroth, J. Bartlett, S. Martel, C. Menard and J. Mollins

Community Health Planning: Determining the Needs of the Community ............................................................ 294
J. D. Heale, G. Webster and T. Abernathy

Expert Systems

Temporal Reasoning and Learning from Cases for Patients Follow-up ............................................................. 302
I. Bichindaritz

Development, Validation, and Evaluation of an Expert System to Provide Decision Support for Nursing Diagnosis in Aged Care ............................................................. 309
B. Koch

Knowledge-Based Interpretation of Serologic Test for Hepatitis in WWW ............................................................. 314
C. Chizzali-Bonfadini, KP Adlassnig, M. Dreihsl, A. Hatvan and W. Horak

Author Index .............................................................................................................................................................. 317
Keynote Speakers
We have built a health care system that is regarded as one of the best in the world. Unfortunately, up until now, the ability of many Canadians to take full advantage of our facilities has been limited by geography.

Information technologies are leading us into a new era in the practice of medicine. Distance is becoming less and less a factor in providing health care. Knowledge and discovery can be shared quickly with colleagues in every corner of the world.

While adapting to new technologies is never easy, Canadians are responding enthusiastically to the challenges involved in developing telehealth and telemedicine. The field draws together Canadian advances in telecommunications and the expertise of our health care system.

Over the years, Canada has achieved a reputation for excellence in diagnostic imaging and telemedicine, distance health education, and simulation and multi-media health education. We want to build on these achievements.

What is the Government’s role? We have updated the legislative, policy and regulatory rules. We are encouraging new services, such as global satellite and wireless cable systems, to enable high speed data exchange and to extend coverage to under-served areas. We are also encouraging companies to create alliances to pursue international opportunities. And we will continue to promote the research and development that will keep Canada on the leading edge of technological change.

In the end, our success in making the transition to an information society will rely upon our ability to establish partnerships among governments, private industry, labour and associations. Together, we can help Canadians to take full advantage of new technology and its ability to bring positive change to health care, and so many other aspects of our lives.
Information Systems Development and Health Sector Reform

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Keywords: health sector reform, systems specification, systems implementation, standards, technology assessment, international cooperation.

Abstract

Although information systems have been long recognized as key elements for the management and operation of decentralized and participative value-added health services, in the enhancement of the quality of individual patient care, and in the monitoring and control of public health actions, a number of obstacles continue to be major hindrances to their deployment in the health sector: adequate solution packages; conflicting or redundant standards, component functionalities and data definitions; data-driven development projects; technology platform imposed development; limited investment and the limitations of decision support functions in general applications. This situation has been compounded by the fast paced changes and requirements brought by health sector reform processes. Changing implementation environments, variety professional and institutional objectives, and the multiplicity of settings in which the sector reform is being conducted, represent a great challenge to information systems developers.

The author considers the need for systems specification strategies oriented toward the achievement of long-term benefits. Application development must emphasize greater intrinsic value, longer life cycles and technology-independent development of data definition standards, common systems functions and data manipulation methods. The model's aim is to separate long-term knowledge and conceptual assets from implementation environment short-term technological assets, particularly aspects related to procedures and to hardware and code platform issues. He recommends the development of a common set of specifications and standards appropriate to the day-to-day operation and management needs of health care services and public health interventions that considers the requirements for data exchange among different financing agents, providers, and governmental agencies. The use of a common set of specifications enable developers to draw on a pool of shared knowledge and provide systems professionals with the opportunity to focus on applications using a general framework that will ensure consistent linkage among different applications.

The social areas, and especially the health sector, suffered a major impact as a result of the profound social and political changes of the last decade, the ongoing process of economic globalization and interdependence, and the harsh realities of increasing income disparity and structural readjustments taking place practically in all societies. The loss of the capacity of the State to maintain viable social benefits systems, the failure of the public sector in the provision of health care when faced by the explosion of the demand, and the mounting costs associated with redundant and many time conflicting health care models and interventions, have motivated governments to find new strategies for the sector. Similarly, the disenchantment with the biased political discourse that dominated much of the public health arena during the 60s and 70s, and the realization of the impossibility to accomplish the postulates of Alma-Ata and Health for All by the Year 2,000, have stimulated the search for alternative forms of health care and the revision of institutional and professional categories roles.

Health information systems and technology roles are also changing [1]. Although major gains have occurred in technological aspects of information management and systems implementation, most health care institutions in developing, and even in some developed countries, have not fully benefited from such advancements [2]. Reasons for the poor permeation of informatics into the sector include: inadequate solution packages; multiple experiences with conflicting or redundant standards, component functionalities and data definitions; data-driven development projects;
technology platform imposed development; discontinuity of investments; and the limited number of systems with functions directed to the support of decision making processes. The public sector faces three major challenges in the deployment of health and health care informatics applications: cost, accessibility and impact on the quality of health care and health status - not surprisingly, those same issues form the core concerns of the health reform process being discussed or implemented in most countries.

1. The Sectoral Reform

Essentially, "health sector reform" proposals and initiatives are grounded in: the universalization of a high cost-benefit basic package of health care services; a set of standardized public health interventions; cost containment and recovery; the recognition of the role of the non-public subsectors; the decentralization of the administration and operation of health care services; and intersectorality [3, 4, 5, 6]. New care systems are oriented toward primary care, centered on people, focused on quality, sound financing, and stress explicitly defined health gain targets. The reform can only take place in a scenario where there is a coherent overall policy for the sector consonant with the socioeconomic, health status and infrastructure conditions of each country. We expect new functions for users and providers and the involvement of new professional categories and local governments [7, 8, 9]. To achieve this undertaking, factual evidence must be gathered, processed and analyzed and the reshaping of health care delivery and the strengthening of management will require a well developed informational infrastructure and validated knowledge bases.

There will be major changes in the manner health care is provided and a growing separation between organizations that provide, regulate and finance health interventions [10]. Health organizations are already moving away from the reactive delivery of care to a more proactive management approach of the health status of individuals and population groups and the mission of organizations will be constructed considering the perspective of the client and other social actors involved in the health intervention processes. In market economies, fierce competition, the merger of provider organizations, aggressive contracting by payers and increasing involvement of employer and government purchasers have characterized the changing process of health management [11, 12].

2. The Implementation Environment

There will be not one single care system but a variety of options appropriate to local needs and infrastructure. In this context, negotiation and consensus are the most important characteristics of managers and organizational reengineering and changes in the traditional organizational culture and leadership will be necessary [13, 14]. Improvement of information handling is the key element for the management and operation of the decentralized and participative value-added health services, in the enhancement of the quality of individual patient care and in the monitoring and control of public health interventions.

Although clinical decision support applications have been around for a longtime, pivotal limiting factors for the utilization of direct clinical decision support, continue to be the difficulties in assigning values to clinical data and our still superficial knowledge and uncertainties of the basic mechanisms of health and disease. A major challenge in this new area will be how to systematize and integrate such knowledge into health practice and needs [15, 16, 17]. At the frontier of possible areas for systems implementation, are applications of knowledge related to the functioning of human organisms, to the pathogenesis of infirmities and their therapy and the ecology of health conditions and their determinants.


With the variety of needs and different perspective of users, providers, managers and other social actors involved in the new "reformed" sector, the health information infrastructure must be adaptive and centered around the requirements of each particular environment. However, to bring together the knowledge about the information requirements and language of managers and health professionals in a structured format is a difficult process [14, 18]. Detailed and precise knowledge of organizational processes is a form of wealth and systems specification is a form of knowledge management. One can look at systems specification as a form of collective knowledge-sharing but, unfortunately, one frequently faces great difficulty in defining user required functions [18]. A major problem in systems specification refers to persistent ambiguity in objectives and functions wanted - health sector applications may reflect the chronic problems of the sector: lack of agreement on priorities, lack of a coordinated approach to problem solving, poor
definition of contents of care and of minimum data sets to support decision making. Failing to resolve ambiguity in application development represents a serious risk and may surface as conflicts, low usability and inappropriateness. A shared mission statement, robust requirements process, peer reviews of critical specifications and user involvement in the design process will go a long way to prevent future problems.

4. A Systems Specification Model

Investment in information systems and technology must be linked to the right strategy to achieve long-term benefits. Greater value and application products longer life cycles can be achieved in information systems projects when effort is directed to technology-independent development of common information functions, data standards and manipulation methods established across all applications.

Given today's rapid and often unpredictable changes in the economics of health, in the organization and strategies of health services, the growing competitiveness among health care providers and the changing of information requirements, health organizations must realistically expect that their information systems will be changing accordingly. This does not infer that organizations should abandon strategic systems planning - what it does mean is that organizations must plan to have a way of accommodating the requirements of changing environments. In fact, most of the typical functions and procedures needed for the day-to-day operation and management of patients and health services deal with well-defined requirements involving recording, storing, processing and displaying of a limited data set and many basic transactions are independent of policy changes.

Appropriate systems specification process addresses the logical requirements of systems and avoid the temptation of technology driven or imposed development solutions. The objective is to detach issues related to the physical implementation of an informatics solution, with its questions of software and hardware platform options, functional access and actual application development, from the more permanent logical "knowledge" assets, represented by information structures standardized at a higher level of the systems architecture. The aim of the model is to separate long-term knowledge assets from the implementation environment associated short-term technological assets, particular procedures, hardware and code-related issues. This will leave room for autonomy regarding physical systems development, implementation and adaptation to user needs. The idea, therefore, is to be able to carry the knowledge-sharing assets of systems specification across different generations of systems without suffering from losses due to technology-induced innovations, like for instance, the introduction of a new database management platform or operating system, and avoid being caught into a short-term reactive behavior dictated by the "du jour" technological option.

5. Promoting the Use of Common Specification Standards

When designing health applications the aim should be to promote the utilization of an agreed common set of functional and data content specifications standards defined for the whole health sector at a national or even international level, as has been the case in the European Union. It involves the definition of the characteristics of systems application modules, functionalities desired and selection of core data elements in the context of an integrated, scaleable and platform-independent logical solution. Appropriateness of the technology, cultural and language issues, models of health care institutional organization and delivery; acceptance, and systems cost-benefit are major concerns of developers and users. They all play a fundamental part in the selection, form of implementation and operation of informatics applications.

Use of common specification standards will enable health application developers to draw on a pool of common knowledge and avoid redundant or repetitive developments. Such specifications will help the exchange of data across different providers, financing agents and governmental agencies. They will further assist systems professionals to focus on any particular area of application using a general framework that will ensure consistency across different applications - this is especially valuable for the drive toward corporate approaches to management and integration of information systems and long application life cycles. By providing consistent specifications for all application areas, common systems standards also will leave developers and users free to concentrate on the issues that are particular to each implementation environment, such as local priorities and organizational structures.
6. Implementation Issues

A review of the extensive experience in the area shows that there is a broad spectrum of possible applications that can take advantage of current technology and there are many options for each application area. The selection of one or other technological option will depend on existing organizational and technological infrastructure and local requirements. Chief concern regarding the development and implementation of health information systems applications, is the search for solutions to infrastructure problems, user interface and to health-specific developments. They should provide technical answers to:

- Benefit health sector clients by improving equity and access to services and the quality of care.
- Support information needs of health professionals, managers and researchers and client requirements.
- Promote the development of medical and organizational infrastructure most appropriate to the methods and technology of computing and telecommunications.
- Manage the knowledge content of applications and roles and responsibilities involved.
- Foster the multi disciplinary approach and strategic perspective required to take full advantage of health information systems applications.
- Face the variety of needs and implementation environments found in different countries or a single country.
- Establish policies and market foundations to nurture the growth of appropriate and accessible health information systems applications.

A significant issue in most developing countries relate to access to technology and to the availability, level, quality and cost of technical staff support and technical services. In most places only few computers or old generation equipment are available to direct patient care users and generally most professionals lack basic computer knowledge. Illiteracy is a major barrier to consumer-oriented health applications.

Technology assessment is too important to be left to technologists, medical specialists and service providers alone, as they have a tendency to focus exclusively on innovations with narrow applications. Appropriateness of the technology, cultural and language issues, models of health care institutional organization and delivery; acceptance and cost-benefit of systems are major concerns of developers and users. They all play a fundamental part in the selection, form of implementation and operation of informatics and telecommunications applications. Notwithstanding the fact that the lack of information systems has been shown to be one reason for inequalities of access and care quality among individuals and society groups, the inappropriate implementation of applications may indeed widen the gulf between the have and the have-nots.

7. Partnerships as Solution to Systems Implementation

Technical knowledge, experience and financial investments needed to establish large and complex information system projects require tapping into resources and expertise that no organization singly detains. Public and private institutions, academic organizations, the industry and financing agents must find ways to pool their assets through project partnerships and add social value to applications of informatics by providing new employment opportunities, socioeconomic development, educational opportunities, promoting health and supporting cost-effective health services.

In the international setting, cooperation between developed and less developed countries is essential but special care must be taken to avoid interventionist behaviors that ignores host perceived needs instead of real needs, fails to understand host capacities, demands action without allowing sufficient time for conceptual assimilation, neglects cultural constraints and ignores host's knowledge basis. As in many other areas of international cooperation the danger is to have too much too soon or too little too late. A possible framework for collaborative work should include support...
to international health issues, health care reform implementation, application development, education, and economic and technological cooperation [19].

Consistent to these objectives, the mission of Pan American Health Organization to its constituency - the public health sector of Latin America and the Caribbean Regions - in the area of information systems, technology and information systems management, primarily involves the transfer of knowledge, technical support, facilitation of the exchange of experiences between countries and fostering the use of appropriate technology and knowledge assets [20]. Areas of cooperation include: priority assessment, technology evaluation and selection criteria, implementation issues, emerging technologies linking patients and providers, access to knowledge databases, consumer informatics and the utilization of Internet and Internet-enabled technologies.

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How to get Patients Discharged before they get Admitted

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Just as resource constraint is causing downsizing of health care institutions, increased funding for community based services is generating unprecedented growth outside of institutions. The challenge of managing this growth has not gone unnoticed and many important questions will require answers.

In our own unique Canadian way we have implemented new public policy without any robust methods of determining whether the policy outcomes are those we intended. The questions to be answered are less objective than those we ask in an institutional setting. Health care transactions are framed by admission and discharge in hospitals but have less consensus in a community or home setting.

Clearly, a catch-up strategy will be required - one using the best that information technology has to offer. Some fundamental principals will support how we proceed. First, the target of decision makers needs to be repositioned on outcomes and moved away from transaction as an end in themselves. The efficiency of care means little if the wrong care is provided.

Second, as research becomes more comfortable with N-1 trials, there will be greater opportunity to evaluate the impact of patient knowledge, self-care and supportive environments. Clinical trails will be focused on what they do best: evaluate alternatives.

Third, the new community information networks will require broad access by traditional and emerging care-givers, it will benefit from integration with institutions and centres for population health.

In this way, information technology, in its design and its application, becomes the matrix in which politics, policy and public preference are co-ordinated with health outcomes as the bottom line. The ultimate test is to assure that the patient is discharged before she is admitted.
Clinical Encounter and Data Capture in a Busy Family Practice Environment

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Abstract

When we first started to informatize a clinical encounter, the first model used was the Subjective, Objective, Investigation and Treatment model introduced by Reed in the late 60s. This model was relatively simple: a "free text" environment was structured around the four various headings and the physician simply had to type what he/she observed during the clinical encounter.

Some shortcuts could be used by choosing the investigation from a menu tick-off list, printing it separately and recording it in the investigation section. Also, the printing of prescriptions could be done from the same menu and simultaneously copied on the patient's chart, thus saving time and eliminating the possibility of mistakes. Another option was to use a drug interaction program which would screen the patient's medication list against the ones in the current medication list before the prescription was printed. Scheduling and time-off notes were also easily entered into such a medical record and it facilitated the documentation of such data.

This model has worked very well for me over the past 7 years. I have been using a computer in each examination room to enter my data "on the fly". Even though the backbone of this system remains useful, my program has become obsolete in today's world of minimal data entry, clinical practice guidelines, decision-support systems and readily available medical information during the clinical encounter.

First, let us look at "minimal data entry". This is definitely the most difficult section to deal with and, for the practicing physician, the area of data entry which has the greatest variation in what data is entered during the history and physical. Some models suggest a "tick-off" system which tries to be all inclusive and for which it is difficult to sort the positive from all the negatives. Another model uses the "free text" for which all the data has to be typed -- this is, of course, less than popular with most MDs. Finally, other physicians prefer to use a speech recognition system which still has much drawbacks despite the great advances in that technology.

Since there are as many patient encounters that result in the determination of minor or major problems with, on most occasions, the diagnosis of two or more unrelated conditions, the shorthand text quickly becomes obsolete, unless one limits the patient to bring up only one problem at each visit, which is bound to cause frustration on the patient's part. We have to adopt our charts to the patient's needs and "not the other way around."

One way of solving this dilemma is with the use of pop-up windows which help the nurse and physician conduct the type of investigation and exam that are recommended for particular symptoms or signs. Standard guidelines could be introduced in a template format that could be easily adapted to each physician's practice. Data entry could then be facilitated in that only positive responses or very appropriate negative ones are recorded on the patient's chart, with all answers being electronically stored. However, not all encounters can be entered this way and the need for some free text data entry remains.

Encounters can also be adjusted to reflect the amount of information already known on a particular patient and the same questions don't need to be asked over and over again. Follow-up on a certain illness can also be simplified with shorter data entry reflecting only new data or continuous important data.
With previous software programs, all these adjustments to the questionnaire had to be done by a computer programmer. With newer software packages, the MD can adjust the various questions in the encounter as one wishes to. These encounter questions must not be done in isolation and must be compared with the MD's needs, and reflect both "good medical care" and "easy data entry".

Since these guidelines often do not deal only with the clinical aspect but go into the investigation part and the treatment section, they must be broken up for the physician to deal with depending on what part of the clinical encounter he/she is in at the time.

"Decisions support system" will most likely become the buzzword of the future. These will include clinical practice guidelines and information the MD needs to know during the encounter.

Quick medical references are now available in CDs that can be accessed through a computer network or the Internet, something unheard of just a few years ago. Quick search tools that prevent the physician from having to write the information being looked for, will be one more reason for the physician to use them.
The Importance of Having an Information Management and Technology Strategy

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In the UK, the National Health Service (NHS) is now computerized at the departmental level. Hospitals have systems such as patient administration, out-patients, pathology, radiology, pharmacy, theatres, finance, contracting, personnel. Health Authorities, who hold the money and contract for services and pay for primary care, are computerized and 80% of General Practitioner practices are computerized.

The NHS is now endeavoring to take its next evolutionary step, i.e. integration, within organizations and between organizations including integration across the NHS as a whole. As one of the biggest organizations in the world this is a very real challenge but also a great opportunity.

The health systems in many other countries are at a similar point in their evolution and there are considerable advantages in sharing experience across national boundaries.

Integration is not just a technical matter. It means aligning the business requirements of a number of different people, departments and organizations to increase the effectiveness and efficiency of shared processes and objectives. The major obstacles tend to arise from achieving managerial and cultural change.

The NHS Executive’s Information Management Group is the central headquarters group responsible in England for establishing and implementing NHS policy for information management and technology. Part of its responsibility is to implement a national information management and technology infrastructure to enable the NHS to realize all the potential of IT that NHS-wide integration can offer. A number of studies have shown that the gains in efficiency and effectiveness can be substantial. For example, the NHS exchanges, between organizations, about 1,000 million structured messages. Making these electronic could save up to $150 million dollars per year.

However integration of processes, sharing of information and access to knowledge on nation-wide bases cannot be achieved without the technology and the technology will not be successful without a clear national strategy for creating the technical infrastructure on which integration will rely.

The NHS defined the necessary national infrastructure in 1992 and its implementation is almost complete. Its most significant components were:

- the creation of a unique identifier - an NHS number - for every individual for healthcare purposes
- clarity about national technical, data and messaging standards based on international standards
- the creation of a shared population register of administrative details of individuals
- an NHS-wide system of electronic networking covering data, voice and radio mobile communications
- the creation of an NHS intranet
- a national language for health comprising a national coded thesaurus of all clinical terms used in healthcare (Read coded terms);
- Healthcare and Health Benefit groups;
national minimum data sets;

adoption of ICD-10

a framework for ensuring security and confidentiality of personal health data

a strategy for raising awareness and skills in information management and technology and ensuring a sufficient cadre of skilled information management and technology specialists.

The infrastructure is also complete. Already some very substantial applications are running upon it. There have been some problems on the way but the benefits are beginning to flow and the use of IT is beginning to speed up very significantly.
Student Poster Contest Submission
The Quality of Dietary Information on the World Wide Web¹

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Keywords: Nutrition, Internet, World Wide Web, Diet, Food, Computer Networks

ABSTRACT

The quality of dietary information on the World Wide Web (WWW) is determined solely by the organizations and individuals who publish it. To evaluate the accuracy of nutrition resources on the Internet, a survey of WWW sites that provided dietary recommendations were reviewed and compared to the Canadian Guidelines for Healthy Eating and Nutrition Recommendations for Canadians. Web sites were accessed through “diet”, “food” and “nutrition” keyword searches. Of the 365 documents accessed, 167 contained dietary recommendations. Forty-five percent (n=76) of these provided information that was not consistent with one or more of the Canadian eating standards and included information in the forms of advertisements recommending supplements, herbal remedies, weight loss products and promotion of specific diets. The total number of web sites that provided information that was inconsistent with Canadian guidelines per each keyword search was 25 (29.8%) for “diet”, 11 (13.1%) for “food” and 48 (57.1%) for “nutrition”. Sources of differing information included individual web pages (n=31, 40.8%), private vendors (n=44, 57.9%) and health organizations (n=1, 1.3%). Because Internet resources continue to increase at an incredible pace, health professionals need to take an active role in this technology and develop strategies to address inconsistent dietary information provided through this avenue.

1. INTRODUCTION

One of the most notable developments in computer telecommunications has been the Internet, a global connection of interconnected private and public networks (1). The amount of nutrition-related resources provided via this avenue have also been growing rapidly. Although it is well known that the content of Internet resources vary in quality, no review of the accuracy of dietary information has been conducted. The intent of this study is to examine the consistency of general nutrition recommendations provided on one Internet service, the World Wide Web.

2. METHOD

World Wide Web (WWW) sites providing dietary recommendations were located by entering “diet”, “food” and “nutrition” keywords in the various search engines of the Netscape Navigator, Version 2.0 (2). Documents that were linked to the initial keyword searches were also included in this study. The keywords and search techniques used for this particular study were chosen because it seemed likely that the general healthy population would use these methods to obtain personal nutrition advice. Based on a literature review of resources which assess dietary information quality, it was determined that the provision of national guidelines as a standard allowed for objective assessment of web sites with dietary content.

All sites accessed by the three keyword searches were reviewed by two researchers and a rating scale (Figure 1) was utilized which was based on the Canadian Guidelines for Healthy Eating (3) and the Nutrition Recommendations for Canadians (4). Because Canadian standards are similar to international dietary guidelines, it seemed reasonable to utilize them for this particular study. Inter-rater reliability showed 99% agreement between the two raters who used the measurement tool of this study which exceeded the acceptable level of 70% (6). In instances where WWW
sites were repeated, the particular sites were assessed once. WWW sites that contained no specific dietary recommendations, were under construction or that contained dietary information for specific diseases and disorders were not included.

**Figure 1: Tool For Measurement of Quality of Nutrition Information**

The following applies to Web sites containing dietary recommendations. Please check only one answer for each question. If a site did not provide any specific recommendation related to an item on this questionnaire, please mark “does not apply”.

1. Do the recommendations provided encourage consuming a wide variety of foods?  
   **Yes  No  Does Not Apply**

2. Do the recommendations provided:
   - Emphasize cereals, breads, other grain products, vegetables and fruits?  
   - Suggest that intake should provide 55% of energy as carbohydrate (138 g/1000 kcal) from a variety of sources?  
   **Yes  No  Does Not Apply**

3. Do the recommendations provided suggest:
   - Choosing low-fat dairy products, lean meats and foods prepared with little or fat?  
   - That intake should include no more than 30% of energy as fat (33 g/1000 kcal)?  
   - That intake should include no more than 10% of energy as saturated fat (11 g/1000 kcal)?  
   **Yes  No  Does Not Apply**

4. Do the recommendations provided encourage achieving and maintaining a healthy body weight by enjoying regular physical activity and healthy eating?  
   **Yes  No  Does Not Apply**

5. Do the recommendations provided encourage:
   - Limiting salt or sodium?  
   - Limiting alcohol (no more than two drinks daily or 5% of total energy as alcohol, whichever is less)?  
   - Limiting caffeine (caffeine consumed should not exceed that of four regular cups of coffee per day)?  
   **Yes  No  Does Not Apply**

6. Information in this web site does not recommend the use of specific dietary supplements i.e. vitamins, minerals, weight control products, herbal preparations, etc.  
   **Yes  No  Does Not Apply**

**Total**  

If one or more answers are “no”, this particular web site is inconsistent with Canadian nutrition recommendations or guidelines.
3. RESULTS

A total of three hundred and sixty five web sites were accessed through the various search engines and three keyword searches and these originated from countries that included Canada, Germany, Japan, China, Australia, United States and Switzerland. Of these, 45.8% (n=167) provided specific dietary recommendations and these originated from Canada and the U.S. A total of seventy-six sites (45.5%) provided nutrition information that was considered to be inconsistent with Canadian standards. These sites included recommendations for dietary supplements (n=49, 64.5%), herbal remedies (n=44, 57.9%), special preparations for weight control (n=29, 38.2%) and specific diets that suggested the elimination of certain food groups from one’s daily intake (n=2, 2.6%). Sources of differing information included individual web pages (n=31, 40.8%), private vendors (n=44, 57.9%) and health organizations (n=1, 1.3%)

The total number of WWW sites that provided dietary advice per keyword search were 55 (32.9%), 16 (9.6%) and 96 (57.5%) for “diet”, “food” and “nutrition” respectively. Of the 167 total web pages providing dietary recommendations, the number of sites within each of the keyword searches that were inconsistent with accepted principles were 25 (15.0%), 11 (6.6%) and 48 (28.7%) for “diet”, “food” and “nutrition” respectively. These figures included web sites that were replicated.

4. DISCUSSION

Based on the results of this study, it would appear that this form of computer technology can be a potential source of inconsistent dietary information. Thus, it would seem evident that consumers need to become more aware of how to assess multimedia sources of dietary information.

Information that differs from national guidelines can affect both consumers and health professionals (6-9). Depending on the impact that the Internet will have, public opinion based on inconsistent dietary information could affect sound nutrition education, health care quality and public policies (7).

Because definitions of dietary misinformation vary (7, 8, 9), advice that differs from national standards may not necessarily be considered as inaccurate. The references used for this study (3, 4) were chosen because they are a baseline for general dietary advice utilized by health professionals.

This study focused on the most popular service of the Internet, the WWW (1, 10, 11, 12). Future research in this area could include investigating other search tools and Internet services. In addition, quality of information in other topic areas could be explored.

Professionals who take on the challenge and exploit the Internet’s resources can find rewards for themselves and their clients. At the same time, health experts should be aware that the WWW is a potential source of inconsistent information for the general public. This research would appear to indicate that there is a need to develop strategies to address inconsistent health information provided through this avenue.

5. REFERENCES


The Patient

The majority of patients in today's health care system no longer experience the acute infectious and life threatening diseases that were once prevalent in our society. As medical technology advances and life expectancy increases, today's patient experiences diseases that are more chronic in nature as a result, this new patient tends to require less acute care services, but more, chronic, supportive and rehabilitation services. Some of these services include home care, palliative care, mental health, substance abuse and nutritional assistance. These services are provided by a diversity of health care professionals located in a multidisciplinary health care environment.

As the view of what it is to be a patient changes, so has the concept of health. First, health is no longer considered merely the absence of disease and illness, but a complete state of physical, mental, social and spiritual well-being. Second, this new understanding of health goes beyond just treating an illness or injury; it involves treating the whole person. Third, the term client is now preferred over the term patent because of the overtone of medical dependency. Lastly, being healthy is no longer just maintaining life, but optimizing functional capacity and maximizing the quality of life.

The Health Care Environment and Health Care Delivery

In response to these trends, important changes are taking place in the health care environment and in the way health care is delivered. Factors such as, an aging population, new health care procedures and technologies, and citizens changing expectations of the health care system are driving up health care utilization and, consequently, cost. The health care paradigm of the past was specialty focused, physician driven, didactic, hospital and encounter based and focused on new technology and procedures. In the new paradigm, health care is primary care focused, interactive, outcomes driven and is striving towards a high quality, cost effective integrated delivery system where the physician is a member of the health care team. This results in a health care system that is patient focused and uses integrated, coordinated, multidisciplinary care plans.

Smaller government budgets are driving the need to control health care costs while maintaining a high quality of patient care. The growth of hospitals as centres of excellence, with their associated trends toward high-cost technology, centralisation and specialisation, contribute to the increasing costs in health services. As a result, one of the objectives of health care reform is to move the delivery of health care from the acute care environment to community based structures. One way to achieve this is by facilitating the process of continuity of care.

Continuity of care is the ongoing provision and management of an individual's health care. Crucial to the shift in the delivery of health care from the acute care environment to community based settings is the smooth transfer of care from one group of professionals to another. To provide continuity of care, health care professionals must have rapid access to a client's health information at the point of care. Different health care visits can no longer be viewed as isolated events, rather they must be seen as different points on the continuum that assist health care providers in delivering care in the most cost-effective and efficient manner as possible.

A Framework for Continuity of Care

Clients and their health care needs are a whole and not separate physical parts or events. Nothing truly happens in isolations. Therefore, health care is most effectively and efficiently delivered in consideration of the whole patient and the life span of that patient. This is especially important for the patient and the system in cases where a chronic illness is present. Health care includes a variety of physical, psychological, and social services delivered through acute, ambulatory, primary and home care settings. Further, these services are delivered by a multidisciplinary group of health care providers that interact with the client at different times in the course of a health care problem and the client's lifetime. Considering the above, effective application of continuity of care requires a mechanism to link all
health care settings and providers in the continuum to monitor needs, arrange access to services and to coordinate care over time. This integrating mechanism usually involves a case manager or a database of patient centered clinical information.

Although the concept of continuity of care between different health care settings and health care providers has been advocated for nearly 20 years, little has been done to accomplish it. The predominant reasons are the behavioral and physical barriers to communication and information sharing that exist between health care professionals located at different health care settings. As the new vision of health care emerges, there needs to be a willingness to communicate with an integrated, client-focused information system to support that communication between providers. Essential to realizing this concept is making the right information available to the right provider at the right time. This is especially important for those health care providers caring for clients with a chronic health conditions. These clients can have numerous assessments of their needs and often receive services from a number of health care providers. To coordinate this care, and to control unnecessary, inconvenient and costly duplication of testing or services, providers must have access to information about a client’s medical and social history at the point of care. The information needs to be timely, accurate and consistently defined across all points of care.

The ideal solution is to integrate existing information systems to provide a network connecting all of the stakeholders within the health care system to each other. The goal is to design a common database that incorporates all of the patient information required to support each of the decision makers. Before a database can be defined however, the data being collected must be standardized. The first key to standardizing this data collection is to define a minimum data set (MDS) which defines the information that needs to be shared among providers to ensure continuity of care.

Minimum Data Set

A minimum data set (MDS) defines a core of common data elements and serves as a uniform data collection tool for care across the continuum. It is essential to support decision making and can meet the different needs of health care professionals located in different health care settings. It is also an essential means of communication. Lastly, it is also a set of minimum specifications for the design and development of information systems. Although most information systems can be used to collect and store many additional data elements, the MDS covers the data elements that have universal application.

There are currently many data sets being developed. The following table outlines the most common ones although most exist more as a concept than a reality.

**History of Minimum Data Sets**

<table>
<thead>
<tr>
<th>Development</th>
<th>Category</th>
<th>Focus</th>
<th>Example Types</th>
</tr>
</thead>
<tbody>
<tr>
<td>First Generation</td>
<td>Minimum Data Set</td>
<td>Statistics, Episodes/Administrative/Medical Services/Administrative/Nursing Encounters/Administrative/Medical Services/Administrative/Nursing Health Professions</td>
<td>Vital Health Statistics, Uniform Hospital Discharge, Long Term Health Care, Uniform Ambulatory Medical Care, Home Care &amp; Hospice, Nursing MDS</td>
</tr>
<tr>
<td>Second Generation</td>
<td>Essential Data Set</td>
<td>Domain Centered</td>
<td>Maternal Health</td>
</tr>
<tr>
<td>Third Generation</td>
<td>Continuum of Care Data Set</td>
<td>Patient Centered</td>
<td>??</td>
</tr>
</tbody>
</table>
Research Question

What is the patient centered Continuum of Care Data Minimum Data Set and how is it determined?

Methods and Materials

The chronic health care problem chosen to study the development of an essential data sets for continuity of care was AIDS. The information required to support decision making for continuity of care process for a client diagnosed with AIDS was identified. The care of AIDS patients demonstrates the need for good communication and sharing information. It is a chronic health care problem the treatment and management of which is information intensive and it requires a multidisciplinary, multi-agency approach that spans the continuum of care.

The first step in identifying the Continuum of Care MDS required identifying the common core elements that needed to be shared between providers and was determined by system analysis and data modeling. This MDS is the first step required to build an information system that would help overcome the barriers to communication and promote linkages between health care providers located at various health care settings. Use of these links will reduce the duplication of tests and procedures, allow more efficient coordination of resources, reduce the number of inappropriate hospital admissions and re-admissions and allow health care providers to become more responsive to a client's changing health care needs.
A Bottom-up, Concept Based Methodology for Indexing and Searching MEDLINE

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Keywords: information retrieval, MEDLINE, automated indexing

Abstract

Despite the amount of effort committed to the problem, difficulties still exist over how to effectively represent and retrieve MEDLINE articles. Attempts to automate the indexing process and improve on Boolean MEDLINE searching have typically been "bottom-up" word-based approaches or "top-down" knowledge-based strategies. Using a clinically oriented subset of articles, I compare a bottom-up concept-based method called Latent Semantic Indexing (LSI) with a word-based model (SMART), a knowledge-based method (SAPHIRE), and regular MEDLINE searches by novice, expert and librarian users. The LSI model achieves higher mean precision than novice or expert physician searchers using regular MEDLINE, and the best performance of the automated indexing methods. The results suggest that rather than attempting to incorporate domain knowledge into information retrieval (IR) systems, we should make better use of the information that already exists in MEDLINE abstracts.

1.0 Introduction

In spite of advances in hardware and software technology for searching bibliographic databases, physicians and other health professionals are not keeping pace with the biomedical literature. One reason for this fact is that many people find it extremely difficult to find relevant information with current information retrieval (IR) systems. Effective on-line searches require users to be well acquainted with a controlled vocabulary such as the Medical Subject Headings (MeSH); few have mastered this skill. The volume of information available to MEDLINE searchers is overwhelming, making the task of sorting desired output from a query difficult and time consuming. Often users must revise queries many times in order to define all of the synonyms necessary to match the desired concept. Further complicating the issue, the reliability of manual MEDLINE indexing is relatively poor, ranging from 31-60% in one study. As the consistency of indexing is directly correlated to search quality, it has been suggested that automating the MEDLINE indexing process could reduce reliance on MeSH, and possibly improve retrieval performance.

Attempts to address these problems in IR research have been "bottom-up" word based approaches or "top-down" knowledge based strategies. This paper discusses the strengths and weaknesses of current approaches, and describes an experiment that compares the performance of existing methods to a bottom-up, concept based method called Latent Semantic Indexing using a test collection of MEDLINE abstracts.

1.1. Bottom-up Word-Based Methodologies

Most distributions of MEDLINE use the easy to implement Boolean model despite the drawbacks: no control over the size of the output; queries are very sensitive to the choice of retrieval terms; no way to represent the varying degrees of term importance in a Boolean query; and constructing queries becomes increasingly difficult as the query becomes more complex. The vector space model (VSM) is capable of automated indexing, and overcomes most of the limitations of Boolean searching. During document indexing, words that exist in a stop list (commonly occurring words which have no semantic content) are removed from documents in the collection. Many systems utilize a suffix-stripping technique called stemming to reduce terms to their root form. Often, terms are weighted to reflect their importance; the terms that occur frequently in a document, but infrequently in the rest of the collection.
receive the highest weights. Each document is then represented as a vector, or column, of weighted word stems, and each row of a document vector represents the importance of the terms in the document. The similarity of documents to a query is typically calculated by the cosine of the angle between the query and document vectors in the space. This allows documents to be ranked according to their similarity to the query, so that the size of output can be controlled. Queries are less sensitive to individual term choices than in the Boolean model, and the VSM can deal well with both short and long queries, since any form of free text can be used as a query.

1.2. Top-Down Knowledge-based Methodologies

Despite the success of word-based indexing and retrieval, another faction of researchers maintain that word-based statistical methods have merely, "picked some of the low hanging fruit off the IR tree,"[7] and that a deeper semantic interpretation of texts and queries will be required before IR can reach its full potential. This approach advocates the use of available knowledge from the domain to aid indexing and retrieval.

In the context of information retrieval systems, a knowledge base is a mapping between the concepts commonly used in a domain, and their representation in an index. Typically, a knowledge base includes a description of major concepts of interest, as well as information about how the concepts are related. Numerous representation schemes have been developed for knowledge bases, including conceptual graphs, frames, scripts, and cases. Many different approaches have been tried, but the general idea is to apply a particular semantic structure designed for a particular field, and combine it with some form of rules for traversing the structure. SAPHIRE is an example of a well known knowledge-based IR system designed specifically for searching health literature. SAPHIRE uses the Unified Medical Language System (UMLS) Metathesaurus to identify all concepts in a document. Then the system performs automated indexing based on UMLS concepts, rather than the words in the text.[8]

Knowledge-based approaches to health care IR sometimes perform successfully in well circumscribed areas (e.g., articles about AIDS), but have not scaled up well to broader domains (e.g., health in general).[8] The use of large knowledge bases for information retrieval is constrained by a lack of proven methods for determining what knowledge is actually required for a particular field, how to best represent knowledge, how to isolate pieces of knowledge from a seemingly unlimited context, and how to efficiently update existing knowledge bases.[9]

1.3. A Bottom-Up, Concept-based Methodology

Latent Semantic Indexing (LSI) is an extension of the VSM that derives virtual concepts for indexing and retrieval purposes.[10] This is accomplished by simultaneously modeling all of the interrelationships among words in each document and the collection as a whole. The model is constructed using a Singular Value Decomposition (SVD), a dimension reduction technique related to factor analysis. For the purposes of information retrieval, SVD is a technique for deriving a reduced set of uncorrelated indexing factors from the original term-document matrix. Loosely speaking, the factors can be thought of as virtual concepts that represent the extracted common themes of many different documents. These virtual concepts have no surface level meaning; one might say that they represent the latent semantic structure of documents that make up the collection.

Instead of representing documents and queries directly as sets of independent words, as the VSM does, in the LSI model each is characterized by a vector of weights that indicates the strength of its association with each of the concept factors. Since the number of factors is much smaller than the number of unique terms (typically 100-300 factors are retained), words are not independent in the LSI model. In fact, it is possible for documents or queries with slightly different term usage to be mapped to the same virtual concept. For instance, with an LSI representation, the query "high blood pressure" may be considered very similar to articles that contain only the synonym "hypertension".

Currently, MEDLINE searches rely on manual indexing, an unreliable and expensive process that requires a user knowledgeable in MeSH, the indexing vocabulary. A number of different strategies for automatically indexing MEDLINE articles have been attempted with varying degrees of success. The goal of this study is to determine if LSI can improve on the performance of the word-based VSM and knowledge-based SAPHIRE using a clinically oriented test collection of MEDLINE articles.
2.0 Experimental Set-up

The MEDTEST collection chosen for this experiment consists of 2,344 documents from MEDLINE and 75 clinically oriented queries created by novice and expert physician searchers, and librarian searchers.[11] In this case, the documents are a MEDLINE entry containing a title, abstract, and a set of MESH headings. The collection also includes a list of the relevant documents for each query that is used for performance assessments.

A popular implementation of the VSM called SMART[6] was used for comparison purposes. For both the LSI and SMART runs, the title and abstract sections of all documents were preprocessed in the same manner using the SMART system. Although they are available, the MeSH headings were not used in order to test the efficacy of automated indexing. Words that appear on a 571 item stop-list were removed, and the remaining words were reduced to lower case, stemmed, and weighted using local and global term weighting. For the LSI model, words that appear in only one document were not indexed. The removal of these terms is primarily to reduce computer memory requirements for calculating the SVD. The 5182 term by 2344 document matrix was then reduced to a 200 factor solution using an SVD algorithm. The single occurrence terms removed earlier were later folded back into the 200 factor LSI model by calculating their position in the solution relative to the indexed documents. Queries were also stemmed and weighted using the same procedures used for documents. The cosine measure was used to estimate similarity between queries and documents.

3.0 Results

For evaluating retrieval effectiveness, the conventional measures of recall and precision are used. For a given query:

\[
\text{recall} = \frac{\text{number of documents retrieved and relevant to the query}}{\text{total number of documents relevant to the query}}
\]

\[
\text{precision} = \frac{\text{number of documents retrieved and relevant to the query}}{\text{total number of documents retrieved}}
\]

The results of LSI, SMART, SAPHIRE, and Boolean MEDLINE searches are shown in Figure 1. For comparative purposes, precision was calculated at 0.1 increments in recall for each query, and then averaged over all points. Of the two automated indexing methods used specifically for this experiment, the LSI model had the highest mean precision (M = 56.3%, SD = 0.31), and SMART the lowest (51.3%, SD = 0.28). A Wilcoxon signed rank test of the two means indicated that the differences in mean precision between the two were highly significant. \((Z = -3.617, p < 0.001, 2\text{-tailed})\). The Wilcoxon non-parametric test was used because variances in mean precision varied widely across queries and models.

Results for SAPHIRE and human searchers were taken from published results.[8] The mean results from MEDLINE searching using the standard Boolean interface were lowest for novice users (42.3% recall, 39.7% precision), intermediate for expert physician users (51.3%, 46.6%) and highest for librarians (52.6%, 59.8%). SAPHIRE's performance was better than novice users, but less than MEDLINE experts (M = 42.0%).
Figure 1. Mean Precision at 0.1 Recall Intervals for LSI, SMART, SAPHIRE. Mean precision for human searchers using regular MEDLINE is also shown.

4.0 Discussion

The LSI method produced significantly higher mean precision over both the word-based SMART model, and the knowledge-based SAPHIRE. As Figure 1 illustrates, the differences in mean precision between LSI and SMART are most notable at higher levels of recall. Overall mean precision for the automated indexing LSI method is even higher than expert physician searchers who used MEDLINE with available MeSH headings. However, performance with LSI is slightly lower than the Medline librarian. Average precision for SMART is better than expert and novice physician searchers, and SAPHIRE, but not as good as LSI.

A closer look at some of the query results illustrates how the LSI model's ability to match on virtual concepts enhances its performance over word-based SMART. For one query concerning "temporal lobe epilepsy and psychosis", SMART ranks the relevant documents "Emotions and personality in complex partial seizures" and "Covert complex partial seizures in psychotherapy" 597th and 1075th respectively because they share no terms with the query. LSI ranks the same documents 5th, and 34th correctly picking up on the theme of the articles. A similar example is "pharmacodynamics, uses and side effects of cyclosporine". The relevant document #935 describes the toxicity of cyclosporine used in allotransplantation in a clinical trial, but does not specifically use the terms, "side effects". SMART ranks this document 90th, LSI ranks it 9th. In another query about treating "not yet diagnosed fever", SMART incorrectly gives a rank of greater than 66 to half of the 45 relevant articles. Many of these articles contain phrases such as "fever of undetermined origin", "unexplained fever", or "fever of unknown cause". LSI captures the context of many of these articles, and gives 80% of the relevant articles a rank of 45 or better (there are 45 relevant articles in total). Ninety percent of the relevant articles for this query receive a ranking of 59 or better with the LSI method. LSI integrates information from many terms across a range of articles in the collection, making it superior for queries which contain non-specific terms.
Why do LSI and SMART perform so much better on this test collection than SAPHIRE, a top-down concept-based system? The main reason is that SAPHIRE relies entirely on the UMLS. Although the large UMLS thesaurus has over 78,244 synonyms and subsumes the MESH codes, the Metathesaurus is not exhaustive. Hersh, et. al. note that over one-fourth of the queries in this test collection have medically significant noun phrases that have no representation in the Metathesaurus.[8] Like all knowledge-based systems, SAPHIRE’s performance must depend on an external source whose completeness can not be known in advance.

A small number of queries could not be adequately searched by LSI or any of the other models tested. One of these concerns ativan, a brand name for lorazepam, a common benzodiazepine. None of the relevant articles mention ativan specifically. Only a knowledgeable user would think to search under the generic name or drug category. Regardless of the retrieval system used, there is no substitute for a user that has some basic knowledge of the topic he or she is interested in.

A major limitation of this study is the size and scope of the test collection. Haynes et. al.[11] chose articles for the collection using MeSH and text word queries, so it is likely that additional relevant documents were missed. It is possible that only the LSI system could have found some of those documents.

A number of theoretical and practical implications for indexing and searching the health literature arise from this experiment. With the current test collection, automated indexing (no MeSH headings used) gives comparable performance to manual indexed MEDLINE for novice and expert physician users. Only librarians skilled in MeSH achieve a higher mean precision with this collection than the LSI model. This finding supports the opinions of Hersh[12], Salton[13] and others who have empirically questioned the efficacy of manual indexing.

Information retrieval systems which employ domain specific knowledge may seem like the optimal approach for automated indexing, and improving retrieval performance. However, the results of this study suggest otherwise. SAPHIRE’s poor performance with this collection highlights the fact that thesauri are perpetually outdated, especially in the field of health care where new diseases, procedures, and medications come into existence frequently. In addition, as the earlier query analyses illustrate, the similarity of a query to a set of documents depends largely on context. SAPHIRE and SMART do not account for context, LSI does so explicitly at the indexing stage. The results of this study suggest that rather than endeavoring to incorporate domain knowledge into IR systems, we should make better use of the information that already exists in MEDLINE documents.

One might argue that the most effective approach to enhancing MEDLINE search results is to improve the search skills of users to the point where they are as good as librarians at using MeSH codes. However, MEDLINE users are busy people who have little time or patience to learn the finer points of MeSH.[11] LSI offers another alternative. The test collection used in this experiment includes actual queries from doctors working in a clinical setting. If the results can be generalized to clinically-oriented searches on a larger population of MEDLINE articles, then one could expect the searches of even novice users of an LSI-indexed system to be nearly comparable to librarian searches made with manually-indexed MEDLINE. A future study is planned with a much larger test collection to address the generalizability issue.

5. References


A Methodology for Defining a Data Set for a Computer-Based Patient Record

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Keywords: patient records, computer-based patient records, medical records, data set design

Abstract

The emphasis in health care is shifting from acute care institutions to outpatient and community settings. This heightens the need for information systems to coordinate and communicate about care throughout the community. Computerized information systems can provide simultaneous access to health information to multiple users in separate locations. Computer-based record systems can improve quality and lower the cost of care. However, many of the benefits of this technology can only be achieved if health care professionals directly interact with a structured computer-based record. A longitudinal health record is more important in treating chronic conditions as compared to acute conditions. A methodology is defined to develop a data set for a chronic condition encounter record using non-insulin dependent diabetes mellitus as the example.

There are no standards for the content and structure of medical records. To introduce a computerized record the content and structure of the data set must be defined. This data set will be developed with the collaboration of physicians, nurses and other health care professionals. Involving the potential users in the design process will improve the chances that they will accept and use the record. The data set will be used as an analogue for the patient to test the ability of the data set to support care decisions in the absence of the patient. The potential users of this data set are the best judges of whether this record will support them in providing care.

1.0 Introduction

In many industries, computer and information technology is used extensively; in many instances it has changed the way business is conducted. However, the prevailing means of record storage and information retrieval used in the delivery of health care are paper based.[1] This paper focuses on record use in direct patient or client care rather than administrative support for health care delivery.

A patient record is the repository of information about a single patient generated by health care professionals as a direct result of interaction with a patient or with individuals who have personal knowledge of the patient (or with both). This record is the way caregivers communicate with each other and coordinate patient care.[1] In this sense the record includes such items as test or procedure results even if these are not stored together in one location. When the patient is not present the record is an analogue for the patient. The record is used as a stand-in for the actual patient as it is the only source of information about the patient without contact with other caregivers.

A major disadvantage of a paper record is that the original up-to-date record is only available in one place to one person at any given time, and data are often missing, illegible, or inaccurate.[1,2] Computer-based records have been proposed to allow health care providers to retrieve data simultaneously in separate locations or institutions. This is especially important as the emphasis in health care shifts from acute care institutions to community and outpatient settings.[3]
ITC 1996: Student Poster Contest Submission

The computer-based patient record (CPR) is an electronic patient record that resides in a system specifically designed to support users by providing accessibility to complete and accurate data, clinical decision support systems, links to medical knowledge, and other aids such as hypertext links to clinical guidelines. Such a system provides a new way of storing the patient record. It can ensure the accuracy and completeness of the data and provide advice, such as alerts regarding abnormal tests or drug-drug interactions. Unlike the paper record, the CPR can also provide "views" or different ways of organizing.

2.0 Description

2.1 The Need for Structured Patient Records

Despite the touted benefits and development since the late 1950’s, use of computer records by health care providers for patient care is rare. Most of the early systems resulted in resounding failures. The main problem in developing CPRs is the difference between the existing paper record and the structure needed for a computer-based record to be effective in health care. The traditional paper patient record is unstructured, mostly free form text, with subject headings or dividers to separate sections. There are no standards for the paper record apart from general guidelines on which sections to include. Moving this record to a computer merely adds the burden of a new form of recording data.

The benefits of CPRs are contingent upon the amount, type and reliability of the information they hold. Medicine does not have accepted content, recording or organizing standards for patient records except when pre-formatted forms are used. Before a CPR can be designed the content and structure of the record must be defined otherwise the record could be created using a word processor and free text. This would not allow the application of decision support tools and structured views of data, it would merely make the record more legible and available.

2.2 Direct Interaction with Health Care Professionals

Many of the benefits of CPRs are only realized if health care professionals have direct real-time interaction with this record. Changing the way physicians, nurses and others record patient and care information may require changing their attitudes and behaviours. If a new system is developed with the participation of health care professionals and improves their ability to care for patients, the system is much more likely to be accepted and used. Caregivers, especially physicians, have often been ignored in information system design. Many computer systems developed for hospital or medical use focused on administration and finance, and were not designed to support care delivery. When the potential users do not participate in and direct the development of a new system, the new system may be resisted or not used at all.

2.3 Problem Description

There are many studies that show how information in a CPR can be used to improve the efficiency and quality of health care. But groups that look at CPRs rarely discuss how data will be entered into the system or define a methodology for designing a computer system for use in patient care. Direct data entry and documentation of clinical reasoning or rationale have largely been ignored by the developers of CPR systems.

In designing and implementing CPRs the complexity of medical practice has been underestimated. Medical practice often deals in uncertainty, opinion and probabilities rather than precision and concrete conclusions. Potential users are the best judges of whether a system will support their work. In the last three to four years the literature shows great interest in involving physicians, including those outside of academic medical centres, in computer system testing. However, this focus seems to be on rigorous scientific testing of whether systems can improve the overall quality or efficiency of care rather then testing if the record effectively and efficiently supports health care professionals in their individual roles.

The data elements necessary in the CPR are predictable and are those which are relevant to the clinical decision maker. In general, this includes a description of the patient in sufficient detail to support the application of clinical logic. The only persons capable of deciding when a data set meets this criterion are the clinical decision makers. A similar consensus approach was used to adapt clinical guidelines for the continuing care of patients with diabetes.
mellitus. The guidelines were subsequently implemented electronically with broad support from the primary care physicians using them. [20]

The way to begin defining a data set is to define a record for one condition or illness; a record that will be used to record information about a patient with a particular condition such as diabetes mellitus. This allows designers to work with a defined group physicians and other health care professionals. With this defined group the patient record can be used as an analogue for the patient.

3.0 Proposed Methodology

The general methodology must not be tied to a particular implementation model; it should produce a conceptual design that is independent of the possible implementation schemes. The record system must be patient centered as the primary use of the system is to support the provision of health care services.

This methodology tests whether health care professionals can provide care at least as well as they do now. This method is used to test telemedicine, radiology and pathology for example. [21] The current method of examining images or body tissues is used to determine the results or diagnosis for a patient. Then the images are transmitted to other pathologists or radiologists using the proposed methods and their findings are compared to those determined with the current methods. This methodology will put physicians and other professionals in their accustomed roles to test the power of the record to support patient care.

Defining a data set should be done using paper forms as these are easy to adapt and they present information in a familiar way. Even screen forms can be distributed as paper prototypes as they can be quickly changed and do not tie designers to a specific mode of implementation. [22] Introducing the burden of data entry on a computer could confound the results. [5] The testing methods will not determine the method of implementation, the conceptual design would be used when formulating the implementation design.

3.1 Define the Initial Data Set

The data set will be developed through a structured systems analysis approach in which the health care professionals are viewed as operational users. [23] Interviews and observation will be used to determine work processes and information use. The existing methods, forms and records used in patient care will be examined. All of this will be used to determine the initial data set (see Figure 1).

```
System Analysis of Existing Records and Information Flow
   ↓
Define Initial Data Set
   ↓
Refine Data Set with Focus Group
   ↓
Test Data Set in Clinical Practice
   ↓
Test Data Set as Description of Patient and Care
```

Figure 1 Steps in Methodology for Defining a Data Set

3.2 Refine the Initial Data Set

The initial data set will be refined in collaboration with a focus group drawn from the groups of potential users involved in direct patient care. These groups will include physicians, nurses, dietitians, technicians and social workers. The data set, with a definition of every data element, will be distributed to the focus group. Participants will be asked to become familiar with the data set and compare it to patient records and notes they are currently using.

The designers will meet with the focus group to determine changes to the initial data set. The designers will then meet with the professionals participating in the study to gather their comments and requests for changes. The focus
group and the investigators will select the data items to be used in further testing. The elements of the data set will be organized as required by the professionals groups who will record and use these items. Paper forms will be developed, using this form of organization, for use when patients are seen. Each form will have spaces for the care provider to enter comments about the form and to record patient information that he or she feels was missed using the data set. This feature will not only provide feedback to the investigators, but will also assure care providers that they are not being told how to care for patients.

3.3 First Use of the Data Set

The resulting forms will be used by participants in the focus group when they are seeing patients. In this first practical test the data set is tested against the current method of describing patients and care. If the participants in the focus group are satisfied that the forms can be used to describe patients and their care, they will each use the forms to see a range of patients. If they are not satisfied with the forms, the forms will be further refined and retested. After a member of each professional group has used the data set to describe patients and their care, the next stage of testing will begin.

3.4 Testing if the Data Set Describes the Patient and Care

The ability of the product to describe the patient will now be tested without the patient. The patient descriptions recorded by a focus group participant will be separated from the care description. This description would be used by other members of the same professional group to make decisions about the patient without having the patient to examine. The ability of these professionals to make decisions about patient care will be compared to decisions made when the patient was seen by the focus group participant. The professional group rather than the designers are the ones who will decide whether the care decisions fall within the range of acceptable practice.

3.5 Repeating Steps in the Methodology

As in many design life cycles, parts or entire steps in this methodology can be repeated. At any point in the methodology, early stages can be redone if testing shows that this is necessary. As well any of the steps can be reiterated to retest the data set.

4.0 Conclusions

This methodology outlines how to refine a data set as it is tested for its ability to support health care professionals in their individual roles. Using paper forms and screen prototypes rather than extensive computer programming a series of these tests can be done quickly and cost effectively. Using paper forms allows health care professionals to concentrate on delivering care rather than learning a new computer system or program.

A data set would be developed for a computer-based patient record for patients with a diagnosis of a particular condition such as diabetes mellitus. The data set for the record would first be tested against existing methods of recording patient and care information. The data set would then serve as a stand-in for the patient, thus testing the ability of the record to describe the patient. This newly defined record can be judged on the basis of its effectiveness and efficiency in providing and documenting care.
5.0 References


Self-Help by Electronic Mail: Perceptions and Meanings of Computer-Mediated Support Communities

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Keywords: electronic mail, electronic support groups, qualitative research

1.0 Abstract

As computer-mediated communication (cmc) becomes more commonplace, more and more individuals are "meeting" and forming relationships via computer networks (e.g. the Internet). In particular, many discussion groups are comparable to electronic self-help groups in that interaction among participants focuses primarily on the common experience of coping with an illness or stressful life situation. Given that electronic support groups are formed and perpetuated solely by textual interchanges among their members, these groups provide unique social environments for the study of how information technology is being used by individuals to form community networks and improve their well being. To date, however, there is little research addressing the nature and functioning of electronic support groups.

The research question addressed by the present study is: How is an electronic support group experienced by its members? Informed by an interpretive and naturalistic approach to social research, this study utilizes qualitative data collection methods (personal document (e-mail) analysis, on-line semi-structured interviews) in order to elicit participants' experiences of a mailing list organized around the issue of support for smoking cessation. Findings of the study are substantive and methodological in nature. Substantive findings describe the experience and meaning of the electronic support "community" from the perspective of its participants. Methodological findings outline the process of conducting qualitative research in electronic settings, including consideration of the applicability and feasibility of qualitative research methods and conventional ethical protocols in these social settings. The research findings represent a unique contribution to self-help research and to research exploring the uses of the Internet in community health.

2.0 The Internet: Mediating Information and Communication

The pervasiveness of the term "information" in the discourse surrounding the Internet (e.g. information highway, information age) overshadows the function of the Internet in mediating communication as well as information. Indeed, while the Internet is used commonly as a way to access and transfer data (information), it also provides an alternate way for individuals to access others (communication). It is with the communicative aspects of the Internet that this paper is primarily concerned.

As cmc becomes commonplace, more and more individuals are "meeting" others for the first time and forming relationships in forums available on the Internet in which individuals exchange messages on topics of mutual interest (Lea and Spears, 1995; Reid, 1991; Leighton, 1995; Smith, unpublished). While it is extremely difficult to estimate with accuracy the number of forums that are available at any given time, a recent estimate suggests that the Internet houses in excess of 31 000 public distribution (mailing) lists, 20 000 Multi-User Domains (MUDs), and 6 000 Usenet groups (Sproull, 1996). Regardless of the exact number, the pervasiveness of such groups attests that these forums are a viable social outlet for their participants. Despite the number of groups that convene "on-line", as well as the impact of communication media on human organization and social relations, there is little research addressing the social aspects of relationship and group formation via cmc.
2.1. Self-Help On-Line: Connecting over the Internet

Certain forums on the Internet are comparable to mutual support or self-help groups in that the topic of discussion is largely devoted to the common experience of coping with an illness or distressful life situation (e.g. Lempert, 1995; Slatalla, 1996). The electronic "conversations" arising in these groups focus on, but are not limited to, information, advice, plans for advocacy, and emotional support related to a common concern (e.g. Madara, 1991; Nader, 1995). Contrary to popular belief, the interactions in these computer-mediated groups are often highly personal in nature. For example, it is not uncommon for members to periodically divulge private information (e.g. telephone numbers) when responding to the personal crisis of another.

2.2 Focus of Current Study and Scope of Paper

The current study addresses the research question of how electronic support groups are experienced by those who participate in them. The first research objective is to describe the experience of the electronic support community from the perspective of its participants. A second research objective is to document the process of conducting research on-line by assessing the feasibility of qualitative research methods (document analysis, interviewing) and conventional ethical protocols (e.g. confidentiality, anonymity) to research in electronic social settings.

This paper highlights and raises for discussion the implications of electronic communication for the objectives of the current study. Given that electronic support groups are formed and sustained solely by textual interchanges, it is essential to consider how this form of communication interacts with and influences the observed relationships and processes in the group. Also, due to the differences between face-to-face and electronic social settings, the study of electronic support groups itself is problematic both conceptually and methodologically.

The following discussion is concerned with communication in *mailing lists* as opposed to other forms of cmc. Based on e-mail technology, subscribers to mailing lists send messages to a central e-mail address where messages are then redistributed to the mailboxes of all individuals subscribing to the list. This is an important distinction since other types of cmc are associated with different patterns of social formation and group norms (Newby, 1994).

3.0 Features of E-mail Technology

The following list, while not exhaustive, provides an overview of the main features of e-mail communication that distinguish it from face-to-face interaction, as well as other forms of cmc.

First, e-mail is aspatial (distance does not affect relationships) and asynchronous (staggered, not sequential) in that messages are not received at the same time as they are sent. E-mail communication is acorporal in that no physical co-presence is required, let alone possible, to form or sustain relationships. Compared to other written media, e-mail is transmitted nearly instantaneously and easily. Also, e-mail messages, once they are sent, are permanent (unless purposely deleted) and can be re-posted or forwarded with little effort. These features, and the implications they have for the objectives of the current study, are outlined in Table 1.

3.1 Implications of E-mail Communication for Participants' Experiences

The aspatial quality of e-mail interaction has major implications in terms of group access. Theoretically, any individual with a computer, modem, and e-mail software can access mailing list support groups despite geographical, physical or social barriers. In particular, for individuals who are restricted by physical, social (e.g. single parent, caregiver), and/or emotional conditions, or who are in geographically remote locations, electronic support groups can provide the means to obtain valuable information and/or to participate in an ongoing dialogue about a shared life circumstance or physical condition (e.g. Jamer, 1994; Sparks, 1992; Harris, 1987; Ferguson, 1987; Slatalla, 1996; Lempert, 1995). Thus, individuals who are unable to attend a face-to-face support group may have access to on-line support groups. Also, on-line support groups can be created that address problems associated with particular barriers that make attending face-to-face meetings difficult or impossible (e.g. Sparks, 1992). While, ideally, this is true, this increased access also presumes a certain level of income and technical competence. Thus, while certain barriers are broken down by computer networking, new barriers are created.
The asynchronous nature of electronic mail is manifested by a certain amount of discontinuity in the flow of messages in mailing lists. Presumably, this 'staggering' of messages in mailing lists influences participants' experiences of the group. For instance, how is continuity preserved in such circumstances? One way in which individuals can enhance continuity is to respond to messages using the 'reply' function which automatically copies the original message and provides a sense of linearity to group interactions (e.g. question, answer). Presumably, there are also other mechanisms by which continuity is created in electronic settings. On the other hand, despite the somewhat discontinuous stream of messages in mailing lists, this asynchronicity allows individuals to send messages at their leisure and when a problem presents itself. This is in contrast to face-to-face support groups in which communication is largely restricted to regularly scheduled meetings in a shared physical context.

Because of its acorporal nature, e-mail is relatively anonymous and this has direct implications for the types of participation that are possible and acceptable in electronic support groups. For instance, it is common for individuals to lurk in the background and refrain from posting themselves. Some implications that lurking may have for participants' experiences are summed up nicely by Lempert (1995): “the anonymous flavour of on-line communication allows introverts to listen in on discussions without feeling social pressure to join in. ‘You can lurk for six months, ... You couldn’t go to a support group and not speak for that long; it would make people too uncomfortable’ ” (p. 2).

Also, the increased anonymity associated with on-line support groups may have implications for participants’ experiences once they begin posting. For example, self-disclosure may be enhanced since this method of communication may be perceived as less intimidating compared to self-disclosure in face-to-face contexts (Lempert, 1995). Perceived anonymity may also have implications for the way individuals present themselves in electronic support groups. Individuals may explore new and different roles than in face-to-face settings at relatively little social cost.

The speed and ease with which messages can be transmitted has implications for the timing of messages in on-line support groups. Most important, this aspect permits individuals to solicit support when it is most needed. This issue of timing may increase the relevancy of help offered in on-line support groups since one can solicit and receive help at the time that a problem presents itself. In particular, this may be an important aspect of groups focusing on conditions in which participants commonly experience times of crisis or intense stress (e.g. alcohol withdrawals).

With regard to message permanency, the re-posting of messages allows for repetition of certain messages over time, and may assist in shaping a group's focus by reinforcing a particular philosophy about the mutual problem or concern. Also, an implication that may be especially pertinent for groups concerned with medical conditions is that inaccurate information, while unintended, cannot be deleted by the sender once it has been posted (Lempert, 1995).

The fluidity of boundaries in electronic groups, while related to the previously described e-mail features, is highlighted to distinguish this aspect of on-line groups as a particularly important feature influencing participants’ experiences. Presumably, fluidity of boundaries is influenced by both the fluidity of group membership and participation, as well as fluidity of implicit ‘rules’ that govern group behaviour (in unmoderated lists). Leighton (1995) sums up this fluidity nicely in this quote from a fellow on-line group member who compares the group to a place where 'people come swinging in on vines, just to see who's hanging out ...'. In the current study, this fluidity of boundaries was witnessed when the mailing list under investigation fizzled out and re-formed into a new group with a new list owner.

3.2 Implications of Electronic Communication for Research Methodology

Due to lack of physical copresence and commitment to space or time, constructing boundaries around an electronic social setting is problematic. In contrast to face-to-face settings, boundaries are not contingent on geography or time, but are more related to computer access (economic structure) and technical competence (e.g., ability to type, ability at written expression). Thus, while it is reasonable to assume that group members share the characteristic of a certain income level, it is difficult to precisely define the parameters that structure electronic groups. Related to the issue of access, while it is generally regarded that information on the Internet is for public access, electronic discussion and support groups often develop their own culture and value system. As a result, participants' may view their interchanges as occurring within a private "place" and do not consider that others are "listening in" to their
conversations. Thus, the borders separating public and private arenas in electronic support groups are unclear. In the present study, while some participants were very supportive of the study, others considered the recording of their archived e-mail postings a serious invasion of privacy.

The asynchronous nature of e-mail communication has serious implications for conducting interviews on-line. In comparison to conventional interview techniques, a list of topics will be sent to respondents who will be asked for commentary. It is anticipated that sending a range of topics will be a more feasible and appropriate way of interviewing since respondents may become impatient with the sequential process of asking questions “one-at-a-time” in e-mail. While the researcher will not be able to interact face-to-face with the respondent, this method of interviewing will allow respondents to reflect at length on questions posed by the researcher and to answer at a time that is convenient to them. Also, the electronic medium is not foreseen to be a barrier to data collection or effective communication since respondents will be well accustomed to this form of expression.

The acorporal feature of e-mail has direct implications for gaining entry to the electronic social setting and for data analysis procedures. In gaining entry to electronic support group in the current study, it was found that it was useful to initially contact the list owner via alternative media (e.g. phone, fax), and then by e-mail. However, this would not be possible in all situations. Also, when contacting potential participants by e-mail for the first time, the researcher felt it absolutely necessary to clearly articulate her background, motives, goals, and plans for communicating study results to respondents. While this practice is not inconsistent with conventional qualitative research protocols, the need to divulge personal information seemed especially pronounced and crucial to gaining confidence and trust from respondents (see Schrum, 1996).

The qualitative analysis of personal documents (archived e-mail messages) is problematic in that e-mail is simultaneously comparable to both informal talk (due to its instantaneous nature) and like prepared, written discourse (due to its reliance on type and lack of visual information). Thus, it is difficult to draw comparisons with studies of face-to-face settings. Furthermore, cues normally conveyed by facial expression, eye contact, and body language are excluded from analysis.

The permanency of e-mail both facilitates and complicates qualitative data analysis. Message permanency facilitates analysis since easily-read transcripts are a direct product of e-mail communication. Furthermore, this “automatic” transcription negates the inevitable layer of interpretation involved in the transcription of face-to-face interviews. Also, the speed and ease of message transmission decreases the turnaround time between conducting interviews and transcript production. On the other hand, e-mail transcripts must be edited thoroughly in order to protect participants’ identities. This involves removing all identifiers that appear within e-mail messages, including e-mail addresses, names, affiliated organizations, web site addresses, etc., as well as entire messages posted by individuals refusing participation in the study.
### Table 1. Implications of E-mail Technology for Participants' Experiences and Research Methodology

<table>
<thead>
<tr>
<th>E-MAIL FEATURES</th>
<th>IMPLICATIONS FOR EXPERIENCES</th>
<th>IMPLICATIONS FOR METHODOLOGY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ASPATIAL</td>
<td>(distance does not affect relationships)</td>
<td>-access (geographical, technological, &amp; social barriers)</td>
</tr>
<tr>
<td></td>
<td>-access (geographical, technological, &amp; social barriers)</td>
<td>-binding social setting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-public/private distinctions</td>
</tr>
<tr>
<td>2. ASYNCHRONOUS</td>
<td>(communication is staggered, not sequential)</td>
<td>-timing of participation</td>
</tr>
<tr>
<td></td>
<td>-timing of participation</td>
<td>-conducting interviews</td>
</tr>
<tr>
<td></td>
<td>-group processes</td>
<td>-getting consent</td>
</tr>
<tr>
<td>3. ACORPORAL</td>
<td>(physical copresence not required or possible)</td>
<td>-anonymity, self-disclosure</td>
</tr>
<tr>
<td></td>
<td>-anonymity, self-disclosure</td>
<td>-gaining entry</td>
</tr>
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<td></td>
<td>-alternate forms of participation or presence (e.g. lurking, posting)</td>
<td>-bodily cues restricted</td>
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<tr>
<td></td>
<td>-role-playing &amp; self-presentation</td>
<td>from analysis</td>
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<tr>
<td></td>
<td></td>
<td>-lack of physical context</td>
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<tr>
<td>4. SPEED &amp; EASE</td>
<td>(rapid, easy message transmission)</td>
<td>-timing of giving/receiving support</td>
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<td></td>
<td>-timing of giving/receiving support</td>
<td>-qualitative data analysis</td>
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<td>-relevancy of support</td>
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<td></td>
<td>-group membership (multiple postings)</td>
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<tr>
<td>5. PERMANENCY OF MESSAGES</td>
<td>(messages are stored unless deleted)</td>
<td>-re-posting and forwarding messages</td>
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<td></td>
<td>-re-posting and forwarding messages</td>
<td>-document data collection</td>
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<tr>
<td></td>
<td>-changing messages</td>
<td>-protecting participants' identities</td>
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<td></td>
<td>-intellectual ownership</td>
<td>-ensuring confidentiality</td>
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<tr>
<td>6. FLUID BOUNDARIES</td>
<td></td>
<td>-fluid membership</td>
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<td></td>
<td>-fluid membership</td>
<td>-fluid group 'rules'</td>
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4.0 Concluding Comments

As information technology becomes more pervasive it is important to address how this technology can be used to benefit individuals and society at large. Researching electronic support groups is one way to obtain this knowledge, for these groups provide unique social environments for the study of how information technology is being used by individuals to form new types of networks and to enhance their well-being. It is important to remember, though, that electronic communication media have implications for the study of computer-networked groups, both in terms of their influence on observed interaction patterns and processes, and their impact on the research process itself.

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Internet Applications - 1

Chair: Jochen Moehr
Canadian Community Health Centres and the Internet: Exploring the Challenges and Solutions

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Keywords: expanding Internet access; Community Health Centres; CHCs; CLSCs; Internet and the health sector; Canada

Abstract:

Community Health Centres (CHCs) across Canada are providing essential health and social services to many communities, and this function is becoming more vital as provinces concentrate on cutting costs and developing more economic and efficient solutions to the current health care system. More than 300 of these community-based organizations currently serve upwards of 13% of the Canadian population, providing a wide range of services in an attempt to promote total wellness in their communities. Over half of all CHCs are located in rural or remote areas. However, despite the apparent need for and success of Community Health Centres, they are among the most under-served health provision groups in the country. Many CHCs lack critical funding and resources, particularly in the area of technology. In this Information Age, the health sector is realizing the importance of using information technologies to increase efficiency, improve services, and maintain viability. Community Health Centres, however, often do not have money for even the most basic technologies such as fax machines, let alone computers and Internet access. CHCs in Canada need to be given the tools they need in order to continue providing quality health care to their communities.

This conference presentation will provide an overview of the current situation of Community Health Centres in Canada vis a vis the Internet and other information technologies. Some of the practical and organizational challenges facing CHCs in this area will be discussed, as well as potential solutions that could and are being developed to overcome these barriers. It is an objective of this paper to facilitate information and resource-sharing and the creation of linkages between Community Health Centres across Canada. CHCs may benefit from better understanding the implications of these new technologies, discovering ways in which their peers are using the Internet, and communicating with one another in order to begin basic planning and needs assessments.

As part of this overview, a brief update on the status of the HealthNet Community Access Pilot will be provided. HealthNet CAP is a collaborative project aimed at educating and providing Community Health Centres across Canada with the tools to help them begin implementing Internet systems and policies within their own context. Part of this grassroots effort involves developing appropriate technical solutions, software, training materials and support resources to help demystify and simplify the technology. Some of these tools and recommendations will be available at ITCH'96 for use by other Community Health Centres.

1.0 Introduction

1.1 Context - The Role of Community Health Centres in Canada

Community Health Centres (CHCs) provide essential health and social services to many communities across Canada, and this function is becoming more vital as provinces concentrate on cutting costs and developing more economic and efficient alternatives to the current health care system. Community Health Centres are community-based organizations focused on primary care, disease prevention and health promotion. CHCs work closely with their communities to assess basic needs, and they often serve high-risk populations that normally have problems accessing health services, such as aboriginal groups, the homeless, new Canadians, and rural populations. The more than 300
Community Health Centres across Canada provide a wide range of services that promote physical, economic, and social health in their communities. More than half of all CHCs are located in rural or remote areas.

Community Health Centres currently serve upwards of 13% of the Canadian population, but this number rises as CHCs are increasingly viewed as viable, cost-effective health care venues. While Quebec has a highly evolved system of CHCs (referred to as CLSCs: Centres locaux de services communautaires) employing over 15,000 people, Prince Edward Island and New Brunswick are only now carrying out pilot projects to assess the appropriateness and efficiency of Community Health Centres as health provision models for these provinces. Meanwhile, the demand for services provided by CHCs is clearly increasing. Numerous rural hospitals are being closed and converted to Community Health Centres, while larger hospitals are reducing services, often aiming their overflow at CHCs. In addition, many community agencies that CHCs normally work with, such as crisis centres, employment agencies, and seniors' organizations, are being threatened or eliminated by government cutbacks, further expanding the need for Community Health Centres in Canadian society.

Despite this need and the apparent success of Community Health Centres, they are among the most under-served health provision groups in the country. In urban communities, CHCs are often overlooked by larger health care institutions because of their smaller size, though they may serve large populations. One serious problem within CHCs that reinforces this inequality, however, is a lack of funding and resources, particularly in the area of technology. In the "Information Age", health care institutions are realizing the importance of using information technologies to increase efficiency and improve services. Larger organizations are often able to find the necessary funding and equipment for such activities. In contrast, smaller organizations like Community Health Centres usually have very limited budgets and bargaining power with corporations, particularly in rural areas. As a result, many CHCs do not have some of the most basic communications tools which are taken for granted by larger institutions. In Nova Scotia, for example, most of the rural CHCs do not even possess fax machines. Community Health Centres in Canada must be given the necessary tools to continue providing quality health and social services to their communities, wherever those might be located.

2.0 Community Health Centres and the Internet

2.1 Current situation

Across Canada, the health sector is becoming aware of the advantages of using information and communications technologies like the Internet in their organizations. Provinces are busy investing in health information infrastructure initiatives, such as PEI's Island Health Information System or the Saskatchewan Health Information Network, in order to increase efficiency and improve services provided to the public. Hospitals at the municipal level are finding new ways to reduce costs and avoid duplication through shared infrastructure projects like the Ottawa-Carleton Health Information Network. Community Health Centres and other grassroots agencies are also beginning to understand the implications of these emerging technologies, but there are still many issues which must be addressed before access can be realized for all groups.

Of the more than 300 CHCs across Canada, very few have any sort of access to the Internet, although this number is increasing slowly, in part due to the HealthNet Community Access Pilot and other projects which encourage and support CHCs in getting connected. The Association of Ontario Health Centres and the Confederation des CLSC in Quebec have both recently begun publishing on the World Wide Web. It is intended that electronic mail, conferencing systems, and online databases may eventually be used by these organizations in order to improve communication and access to information among their constituents. The effectiveness of these sorts of resources and tools is limited, however, when only a small percentage of Community Health Centres in a particular region or province have access to them. Support and resources must be provided where necessary to ensure that all CHCs are able to benefit from new technologies, regardless of their size or geographic location.
2.2 Benefits

Many people still wonder how the Internet could possibly benefit Community Health Centres in Canada, and indeed the answer differs from organization to organization. Although the Internet offers many potential benefits to both health care providers and their clients, it is only by using the technology and applying it in practical and appropriate ways that the real benefits can be revealed for a particular organization or individual. Each Community Health Centre will develop their own uses, depending on their specific needs and clientele. Some major benefits of the Internet to the community health care sector, however, include the following:

- **Improved communication for Community Health Centres across Canada** - Many CHC workers express an interest in using the Internet to communicate with other CHCs in order to share experiences and resources, increase collaboration on projects, mobilize politically, and reduce long-distance telephone charges and travel expenses. These opportunities may help CHCs become more efficient and avoid duplication in their efforts to provide services. Communication may also assist CHCs in overcoming some of their major issues, such as being seen as a viable option in Canadian health reform and gaining support from health professionals, funders and consumers.

- **As a result of the Internet, communication may also be increased with government bodies (eg. Ministries of Health, Health Canada), other social service agencies, clients, and health professionals around the world. Peer-to-peer consultation may also be enhanced.**

- **Improved access to relevant, up-to-date information using various Internet tools** - World Wide Web sites, discussion groups, mailing lists, and on-line databases and journals provide a wide variety of timely, reliable information, as well as increased opportunities for distance education and peer-to-peer consultation.

- **Increased competitiveness in the community health sector** - Increased competitiveness of CHCs has wide-ranging benefits to the entire health sector. The most cost-effective health care organizations will be the ones to survive in this era of cost cutting, and information technologies increase the viability of Community Health Centres, both as a whole and individually.

- **Improved services to the community served by a CHC** - Internet technologies are increasingly being used for telemedicine, remote diagnosis, and health promotion, providing both health practitioners and clients with access to key tools and information. This is especially important for clients who are isolated geographically or due to a physical disability that does not allow them to leave their homes. Community Health Centres can help eliminate some of the barriers facing their clients by publishing locally-relevant health information and communicating directly with members of their community. This may assist clients in becoming more responsible for their own health.

- **Capacity-building within community health centres** - By providing workers in CHCs with useful Internet skills and knowledge, they will be better prepared to access internal resources to develop appropriate solutions to their information and communication needs. In the past, most CHCs have been dependent on external computer consultants to provide key technical services. By understanding the implications of Internet technologies, Community Health Centres will have more control over decisions related to this important area.

2.3 Challenges

The challenges involved in implementing the Internet in CHCs differ according to each organization's needs and resources. Some Centres are very well-equipped with computers and technical support, while others remain technically disadvantaged. Despite the differences, however, there are some common challenges for most CHCs.

By far, the greatest barriers facing universal Internet access for Community Health Centres are technical. Whether it be a lack of adequate computers, modems, telephone lines, affordable Internet access, training resources or technical expertise, CHCs often require support in some or all of these areas. These are major challenges which demand innovative solutions to overcome.
Another issue facing CHCs wishing to access the Internet is the existence of organizational challenges. These may include hesitancy by key individuals or groups within the organization (e.g. Executive Directors, or the Board) who do not approve of the organization becoming involved in technical activities. Human resource limitations are also factors which must be considered, as many CHC workers are already overworked and being forced to deal with other significant issues like budget cutbacks or organizational restructuring.

Psychological barriers also exist within Community Health Centres. Some CHC workers fear technology, usually because they are unfamiliar with it and do not accurately understand its implications. These fears could relate to real or imagined issues, such as security and confidentiality or thinking that viruses from the Internet will make their computer sick. By addressing these fears and educating new users, these psychological challenges can easily be overcome.

Various social limitations also come into play when dealing with organizations and technology. If an organization or group of individuals is not already communicating on a regular basis for whatever reason, the Internet or any other communications tool is probably not going to solve that issue. The Internet is not a panacea, but a tool to facilitate and enhance communication.

The specific challenges facing rural and remote Community Health Centres require special attention when discussing ubiquitous Internet access. Rural CHCs often face more initial barriers to participation, such as a lack of funds, equipment, or local Internet access, as well as being isolated. In contrast, there are more rural CHCs in Canada than urban Centres, and rural communities could potentially benefit more from the use of information technologies in their health centres by using telemedicine applications, communicating with clients who are located over a large area, and reducing the need for costly long-distance telephone calls and travel. These unique challenges mean that rural and remote CHCs are often at a particular disadvantage when it comes to information technologies.

Of course, in most cases, lack of financial resources is the largest barrier to the participation of CHCs in the area of information technologies. In considering most of the challenges listed above, funding could help to overcome them. Since it is not likely that additional funding will be made available in the near future, CHCs wishing to benefit from the Internet must work together to leverage all available resources in order to develop adequate solutions to these challenges.

2.4 Potential Solutions

Solutions to overcome the challenges facing Community Health Centres wishing to access the Internet must be developed in collaboration with each organization, according to their specific needs and goals. The fact that each CHC's situation is different must be understood and addressed, rather than presuming a top-down approach which may not be effective for all groups. While some generic resources and services may be useful for most CHCs, it is important to work at the grassroots level so that each individual organization's needs are met appropriately.

The key to cost-effective Internet solutions is resource-sharing. Partnerships among CHCs and with other private and public sector organizations should be encouraged wherever possible. Duplication of efforts, excess equipment, and wasted money could all be reduced or avoided completely if organizations communicated and cooperated more frequently. For example, larger CHCs which own more equipment or are upgrading could consider lending/giving their older computers to small CHCs who could benefit from these resources. In urban areas, one technical support person could be shared among a number of CHCs to reduce costs.

To reduce the costs related to Internet access, CHCs could potentially avoid duplication, improve services, and reduce costs for all partners in urban areas by sharing the information infrastructure already put in place by other larger health care organizations. OCHIN (the Ottawa-Carleton Health Information Network) provides an effective model for this type of shared system and could be implemented in large communities across Canada. In rural or remote areas where resources are often more limited, different solutions must be developed. SchoolNet and Stentor Corporation plan on using satellite technology to connect remote schools to the Internet. Industry Canada's Community Access Program is also providing funding to many rural communities to create public access sites to the
Internet. The infrastructure created by these projects could be utilized by Community Health Centres in those same communities, again reducing the need for duplicate installations of equipment.

One way to lower the cost of higher-end Internet consulting might be to consider hiring young people who are just emerging from university to work within local CHCs. This group is one of the most experienced in the area of Internet technologies, and could provide both technical skills as well as an interest in community development (e.g. outreach programs). Many young people have a broad range of relevant skills which could be used by CHCs, and yet there are few meaningful employment opportunities for young people to put these skills into practice.

Community Health Centre workers require progressive-minded, supportive environments in which to learn about the potential benefits and uses of the Internet. CHCs which are already connected to the Internet could help encourage other Centres in their activities through a sort of "buddy" or "twinning" system. On-line discussion groups on a variety of topics could also facilitate communication and information-sharing between Community Health Centres, in addition to more traditional means of relating their experiences (e.g. print newsletters, telephone calls).

Other factors which could help facilitate CHCs' involvement on the Internet include the provision of financial or technical support for Centres with very limited resources, such as rural CHCs. Many practical barriers, such as a lack of equipment or training resources, could easily be overcome with the help of some financial aid, such assistance might be provided by provincial governments or private sector partners.

Although it provides important support and useful resources, the HealthNet Community Access Pilot is only one small part of an overall Internet strategy for Canadian CHCs, since the real success depends on participation and input from all CHCs. Community Health Centres must begin planning for the future and communicating with each other in order to develop goals and solutions so that all CHCs can benefit from using information technologies. HealthNet CAP is working to encourage dialogue and cooperation among CHCs, and this role could be expanded in conjunction with the Association of Ontario Health Centres and other such organizations.

Although there are many challenges facing Community Health Centres wishing to access the Internet most CHCs simply require some basic support and direction to help them get started, to begin talking to other organizations and potential partners, and to understand their own needs. This has been a major goal of the HealthNet Community Access Pilot.

3.0 HealthNet Community Access Pilot

3.1 Objectives

The main goal of the HealthNet Community Access Pilot is to expand and evaluate the use of information technologies (Internet) in the community health sector across Canada by developing user-friendly tools and resources that will facilitate access and familiarization to the Internet. HealthNet CAP attempts to educate and provide participants with appropriate tools to help them begin developing Internet systems and policies within their own context. The initial test phase of the project ran from October 1995 until March 1996, with Phase II underway from May 1996 to March 1997.

3.2 Rationale

As described above, Community Health Centres are an important part of Canada's health care system and are suitable starting points for introducing the Internet to communities. CHCs need useful tools that will facilitate efficiency and allow workers to provide better services with fewer resources. Communications technologies like the Internet may be able to assist in this process, improving the ability of CHC workers to share resources and information, access current medical databases and clinical resources, consult with other professionals around the world, and increase technical skills.
3.3 Successes

A combination of community partners and corporate sponsors have been involved in the first phase of the HealthNet Community Access Pilot. Sponsors supporting the project include the Ottawa-Carleton Health Information Network (an initiative of the Royal Ottawa Hospital) which has provided free Internet access to local CHCs, Gandalf Technologies and Bell Canada which have supplied an ISDN line and hardware to connect one CHC's LAN to OCHIN, and the Community Access Program of Industry Canada which provided funding to hire the HealthNet CAP Coordinator.

Community Health Centres participating in the project include Carlington Community and Health Services (Ottawa, ON), Merrickville District Community Health Centre (Merrickville, ON), Somerset West CHC (Ottawa), Sandy Hill CHC (Ottawa), Centretown CHC (Ottawa), Pinecrest-Queensway CHC (Ottawa), and Country Roads CHC (Portland, ON). Most of the 60+ new Internet users within these organizations had little or no prior experience with the Internet.

A major goal of HealthNet CAP was to remove all barriers to participation, including cost. Advice and appropriate Internet connection solutions were provided to each participating CHC at no charge, as well as hands-on training, software recommendations, an Internet training manual, and access to a World Wide Web site specifically created for workers in CHCs. Private and public sector partners were established to help sponsor CHCs, and feedback from users was requested and documented in order to learn from their experiences. The lessons learned, as well as an outline for Phase II of the project, are detailed in the Phase I Final Report, which is available upon request.

3.4 Future Plans

Phase II of the HealthNet Community Access Pilot is already underway, and is expected to run until April 1997. Based on lessons learned and contacts made during Phase I, Phase II will focus on expansion of the project to healthcare organizations (including CHCs) in Ontario, New Brunswick, Saskatchewan, the Northwest Territories, and possibly Quebec. Interest has already been demonstrated by numerous CHCs and potential partners/sponsors across Canada. In addition to sharing the resources and information collected in Phase I, new services that will benefit the community health sector are also planned, such as directories and search utilities.
Is there a Telehealth Industry in Canada?

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Keywords: telehealth industry, telehealth sector competitive framework, telecare, IT and health care

Abstract

Many factors are giving rise to important changes in the health care system. The population is aging and needs more frequent health care interventions. The rising public debt has forced public administrations to cut back on health care expenditures. There is a move to link institutions and cut down on overhead. Health promotion and self-help, patient education and home care are replacing more traditional forms of patient care. Recently government assistance for telecommunications developments in health care is shifting from providing grants for research to developing the health care technology industry and creating partnerships. The Canadian government's strategy for the development of the Information Highway are fostering new applications, collaborative projects, and promoting access to services from the home. In spite of the many factors which would tend to promote the use of telecommunications technology in health care, barriers continue to exist which inhibit their system-wide use. The introduction and development of new information, imaging and telecommunications technologies have often been associated with improved efficiency, productivity and quality of life, but there are still a number of unresolved issues which point to the need for better working partnerships between the private and public telehealth proponents. This paper reports on a study in progress of the Canadian telehealth industry, sponsored by Industry Canada and undertaken at McGill University. Using an industrial sector competitive framework, methods used for data collection are interviews, site visits, focus groups and literature searches.

1.0 Introduction and Definitions

The current study is about the telehealth industry in Canada and is based on a sector competitive framework, a method used by Industry Canada to determine the competitive position of various Canadian industries. The study is funded by Industry Canada, in collaboration with McGill University's Graduate Program in Communications and the Canadian Centre for Management Development (CCMD). At the time of writing, the study is in progress.

For purposes of this study we have defined the field broadly as the use of communications and information technology to deliver health, medical and health care services and information over large and small distances. This definition reflects the changing nature of the twin fields of health and medical information systems on the one hand, and telemedicine systems on the other hand. Historically these fields operated separately but they are now merging because the technology is making it possible and the applications are making it necessary. The terms health care embrace an increasingly wide variety of applications and we have accumulated a data base of over 50 Canadian private-public sector projects. Telehealth includes:

- telemedicine: teleconsultations, tele-pathology, tele-radiology, tele-psychiatry, and so on
- patient and health information systems, networked health databases
- community health information networks (CHINS) and systems using smart cards
- multi-media applications and mediated distance education for health professionals
- inter-institutional health networks
- robotics, virtual reality and 3-D imaging applications
2.0 Framework

A Sector Competitive Framework or SCF, based on the work of American economist Michael Porter, is a disciplined way to look at all aspects of an industry in the Canadian, North American and Global context: its history, technology, trade, investment, human resources, markets, demand outlook, strengths and weaknesses and major challenges. Following the analysis or outlook, an action plan is developed in cooperation with industry representatives - employees and owners.

The SCF has its limitations. It is not necessarily suited to measuring the knowledge economy, but more to the older style manufacturing industries. This industry is not simply knowledge-intensive, it is also innovation-and technology-intensive, involving re-structure and re-engineering if it is to be successfully integrated.

3.0 Methodology

This is a qualitative study. This sector is too new to have produced much hard data available from traditional sources, so we are crafting our own sources. We have conducted 60 interviews and participated in or organized 5 discussion groups with private industry, government representatives, researchers, physicians and association and consumer group representatives. Other than the usual on-line data base services, we are using Internet sources on a daily basis and an electronic newsclipping service provided by Industry Canada.

4.0 Canadian Historical Perspectives

4.1 Early Telehealth History

The fields of telehealth and telemedicine are not new and date back to the early 1900s when electrocardiograms (ECG) were transmitted over telephone wires. In Canada, Dr Jutras, a Canadian radiologist, is credited with having transmitted cine-radiographic images and performed remote control fluoroscopy as early as 1958.

The golden era of telemedicine was ushered in when the governments of Canada and the US sponsored telemedicine experiments and demonstrations with the launch of the Hermes satellite in 1976, and later with the funding of pilot projects on the Anik 1 satellite. What is interesting for purposes of this study is that in Canada as well as in the US, so few of those projects survived through the years to become operational sites, perhaps because these projects were almost entirely technology-driven. There was no time to conduct needs assessments and cost-benefit analyses. As a result, these satellite-based telemedicine projects remained add-ons and were rarely integrated into the health care system as a whole. A recent review of the telemedicine experience in Canada identified 19 telemedicine demonstration projects and 7 active telemedicine sites or services - of which only one uses satellite technology.

4.2 The Age of the Computer, the Internet and Beyond

The advent of powerful computers and communications technologies and the availability of vast amounts of information on the Internet have provided the impetus for this most recent telehealth era. On the Internet itself, you can find ample evidence of the level of activity. The current era started in the mid-eighties and is characterized by linking new technologies, by Community Health Information Networks (CHINS), by systems which respond to new demands, and by the advent of alternative health care institutions in the community which include holistic approaches to health care, and care given in the home.

For the health care professionals, the central focus of this era is the penetration of the electronic patient record, of easy access to vast amounts of clinical information even before it is published, of cheaper and smaller desktop multimedia tools. For the consumer, it is the necessity to seek innovative alternatives to traditional medical care as the state withdraws more and more from this arena, and the greater desire to question established practices and manage one's own health. At the community level, this era is characterized by the gradual disappearance of the hospital as the central authority in health care and the linking together of all the community resources to provide and integrate service to consumers. For the industry, opportunity knocks: the many barriers are still high, international markets are being penetrated, convergence and the information highway are setting the stage for a growing number
of applications and new markets. In Canada, around $11 billion dollars is being spent on researching, developing and implementing telehealth systems, of which one third is from government sources.

5.0 Why This Study

Several factors were instrumental in initiating this study. Consumer awareness and demand are changing. We are all getting older, and older people need more health care. We have a commitment to and a tradition of high quality health care, but it is a 70 billion dollar industry and we must find alternative ways to deliver quality care. The availability of high powered computer and communications technology is driving this industry forward, making it easier to exchange large volumes of information over long distances. Distance no longer matters: whether we are far away from home or home is far away, the technology can usually deliver the information, and even guide or perform the needed therapy or surgical intervention.

Reflecting the government's role in job creation and growth, Industry Canada is working to help Canadian industry to become more competitive. It has opened up its file cabinets and is electronically formatting and distributing reports on all the major industries in Canada. Industry Canada supports timely and equitable access to high quality and affordable communication systems and services and is playing a leadership role in the development of the Information Highway. The first report and the action plan both recommended that health care applications be encouraged and developed.

6.0 Preliminary Findings and Emerging Issues

What follows is a short list of some of the issues which have arisen most frequently in the interviews, the focus groups and in the literature reviews. Some of these issues can actually provide the industry with new opportunities.

6.1 Many Stakeholders with Different Agenda

This is an issue for government. Several types of public, para-public and not-for-profit organizations are involved in Telehealth activity and these many stakeholders hold quite different interests. It does present problems when governments must choose for the greater good amongst the widely diverging interests of so many different groups. Even within the government itself, the interests are widely ranging. No issue claims more attention than the dominant one, that of the cutbacks to health expenditures. Many would claim that the health care system is in crisis, and this is the time to innovate. Technological innovation tends to cost money before it saves it and few studies have given conclusive evidence that money can be saved.

6.2 Privacy, Security, and Confidentiality

So much has been said about this issue already that there is hardly any need to elaborate on it further. Electronic collection, transformation, storage and transmission of data tends to provide a greater vulnerability to breaches of security. Conscious that this is high on the list of deterrents to the use of the Information Highway, Minister Manley announced last May that new proposals for a legislative framework governing the protection of personal data would be forthcoming. There may be a niche for Canadian companies here, especially as some of them already have experience in the encryption business.

6.3 Standards

There is general agreement that this is a complex and urgent issue which government needs to address. It cannot be left to the industry to solve alone. It covers such wide-ranging areas as:

- Data standards
- Telecommunications protocols and standards for interoperability
- Standards for terminal design
- Quality of image and sound
- Standards of practice and nomenclature
For industry, data standards, protocols and interoperability were some of the issues most frequently mentioned. In some cases a mix of cable, telephone, micro-wave, and satellite technology is needed to reach remote locations and even then, the quality is not what was expected. With the recent announcements regarding telephone and cable convergence, these problems of interconnectivity could be solved or they may intensify. The partnership initiative of the Canadian Institute of Health Information (CIHI) may provide leadership in this regard.

6.4 Home Care on the Rise

In Canada as in the US, for decades the mental model of the health care system was the local hospital, often the most visible institution in the community, the largest employer, the tallest building, the location where most medical care was delivered in between the two most important events in our lives: birth and death. Budget cutbacks along with a new conceptual model of the health care system focused on disease prevention, health promotion and primary care are requiring the hospital to relinquish its role as the traditional hub of the health care system. The hospital must reinvent itself. Though telehealth will never completely replace the hospital, the rise of ambulatory care is driving the need for telecare and tele-monitoring systems. Here again an opportunity exists for Canadian companies. The thriving home care industry will increasingly call for well-designed tele-homecare systems.

6.5 Access Issues

There are several types of access problems. The most important are technological, geographic and economic, that is, those who need telehealth most acutely are the ones who have the least capacity to communicate electronically from their homes and communities. Telecommunications technology of the capacity that is needed for most telehealth applications is expensive and not widely distributed in spite of all the hype about the information highway.

6.6 Dehumanization

Neil Postman, in his book Technopoly, claims that medical technology is not neutral, and that even the stethoscope, one of the first of many instruments to be introduced in medical practice, has estranged the doctor from the practice of skillful medicine which begins with listening to the patient, and making careful observations to arrive at an accurate diagnosis. Seen in this light, telehealth would certainly magnify the distance between the health care provider and the patient.

6.7 Professional Fees, Licensing, Training

Many Canadian physicians are not paid for consultations given over electronic media, an important deterrent which partly explains why physicians have mounted research projects rather than become champions of permanent telehealth services. Perhaps this fact alone is proof that the health care system does not accept telehealth as a substitute for the real thing, the actual patient-doctor encounter.

Using telehealth technology, a physician can provide advice to a patient or a colleague anywhere else in real time but licensing and practice arrangements limit that physician to practice in his or her own turf.

A large percentage of the more than half a million Canadian health care workers will be affected by the information highway as the government seeks to make more important reductions by combining facilities, functions and services through networking and linkages. So far we have found only one educational program in Canada which gives guidance in remote medical education but none which trains telehealth practitioners. Nursing and medical schools do not offer extensive medical telematics training, yet it becomes vitally important that future workers be trained to use the information highway securely, and humanely. Home care workers in particular will require skills in the effective and safe use of home care and telecare technology.
6.8 Needs Analyses, Implementation and Evaluation

It is difficult to make a business case for adopting costly technology without a proper needs analysis. Needs analyses may well show that certain technologies would make the organization more efficient, while others should be discarded. Until real demonstrated evidence is provided within the context of the organization and milieu, there is often resistance to change on the part of the individuals.

Closely associated to the problem of needs analyses are those associated with evaluation and implementation. One of the principal barriers to adopting new technologies is that they do not necessarily mesh with planned organizational change. Sometimes this happens because the telehealth experiment or the technology is of limited duration. In other cases, the organizational aspects are mismanaged because these aspects are complex and poorly understood and evaluation tools are inadequate to reflect organizational change. The new system is then doomed to remain outside accepted practices, a novelty in an old, well-established system. After reading many project evaluation reports which do not reflect the range of a project's effects on the organization and its users, one must conclude that good multidisciplinary evaluation tools are simply not available. Research is needed to show how "existing technology can be integrated into health care delivery systems in a way that improves the effectiveness and efficiency of those systems, and methods are needed to evaluate the impact of communications media on those systems that have been developed".

7.0 In Conclusion, Is There a Canadian Telehealth Industry?

In a previous paper, I reported the telehealth industry is fragmented and emerging. Will the above-named issues make things worse for the Canadian telehealth industry? Not necessarily. First, these issues make the entry barriers high, and companies who surmount them and survive ought to be quite successful. Second, some companies may become discouraged with the domestic scene and choose to develop their international markets, where there are growing opportunities. Third, the issues presented here provide many opportunities for new product development, and there appears to be no shortage of applied research and venture capital funding available for r&d. Fourth, the government is no longer able to invest large sums of money for uncertain technological projects. Some government agencies are no longer buyers, they have indeed become merchants, having to find ways to finance and support their organisations, thereby appearing to compete with the private sector.

All of these reasons point to the need for this industry to carve new ways to do business. One way might be to create solid partnerships with the public sector it wishes to serve. Little is known about how to create lasting, commercially viable partnerships of this nature, and thereby lies a challenge to be overcome if this industry is to become established.

8.0 References


Health In Action: A Flagship Project

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WHAT IS HEALTH IN ACTION?

http://www.health-in-action.org

Health in Action (HIA) is an electronic source of information about health promotion and injury prevention programs, projects and research in Alberta. The HIA has information on almost 400 programs, projects and research, in such areas as healthy communities, injury prevention, community nutrition, healthy public policies, maternal and infant health, tobacco reduction, and school health.

Its purpose is to maximize effectiveness of prevention and promotion programs in Alberta by making the best information available to practitioners, funders, evaluators, researchers, and program planners.

Funding for HIA was provided by Alberta Health

Partnership

HIA was developed using a partnership model. The partnership is made up of four agencies: the Alberta Centre for Well-Being (ACFWB), Injury Prevention Centre (IPC), Regional Centre for Health Promotion and Community Studies (RCHPCS), and CCI Networks.

The ACFWB is the lead agency and its director oversees all aspects of the project, including managing financial resources. It is also a point of contact for many administrative tasks such as records of HIA activities, contracts, and communication with other agencies. The ACFWB also identifies sources of health promotion program information.

The IPC conducts the inventory of injury prevention programs, research, and evaluation based upon its research capacity and subject knowledge of injury prevention.

The RCHPCS conducts the inventory of health promotion and evaluation initiatives based upon their continuing involvement and facilitation of research throughout Alberta.

CCI Networks develops and implements the HIA site. This includes the placement of documents, graphics and images to achieve the best effect for users; maintenance and upgrading of information; connections to disparate databases; and technical support to users of the site, including the project partners.

HIA is guided by a regionally representative Advisory Committee whose members are from various fields of prevention and promotion. The project is managed by a Project Team, consisting of representatives from the four partner agencies and a Project Manager.

Development and Milestones

The development and progress of HIA was brisk, as the project went from conception to full operation in only ten months. Several milestones were achieved during that time, including:

- a consultation process with stakeholders across the province, to determine needs
- establishment of an Advisory Board of regional representatives in health promotion and injury prevention, to advise the Project Team on development and implementation
- design and piloting of a survey tool to collect data
collection of data from health promotion and injury prevention programs, projects and research throughout Alberta and entry of that data
- creation of a Website for HIA, including the database, links to other Websites, a survey form, feedback mechanisms and a formal evaluation
- province-wide launch of the HIA project - publication of a user guide, intended as a quick reference for using HIA

Evaluation

Who is Using Health in Action?

As of the July 1996 report, HIA had approximately 23,000 requests for files of information. The vast majority of users of the Website are within Canada. According to monthly statistics, between 50 and 60% of the users can be verified as being in Alberta. However, this figure is likely higher, as it is not possible to verify the origin of all calls.

HIA has also attracted users world wide. Predictably the United States is the most frequent user outside Canada, but other countries include Australia, Costa Rica, Japan, Korea, Singapore, Spain, Sweden, and the United Kingdom.

The information is likely being used in a work setting, as heaviest usage occurs Monday to Friday between the hours of 9:00 a.m. and 6:00 p.m.

Ongoing

On-line mechanisms, such as a feedback email option and a questionnaire provide feedback about use of HIA and information for use in improving the system. From these, and anecdotal information, users of HIA report positive experiences and such benefits as ease of use, increased awareness, and use in program design, implementation and evaluation:

"I only started using the Internet in January and was amazed and relieved at the ease of use of Health in Action."

"I use it for needs assessment, design, implementation and evaluation for program design."

"It's a great place to see what's happening, who's doing what and getting program ideas."

Formal Evaluation

A multi-strategy evaluation, to be conducted in the fall of 1996, will provide more extensive information about how we can modify the system to meet needs. It will include evaluation of the operational framework and processes, user issues, non-electronic access options, and marketing/promotion strategies. On-line mechanisms, stakeholder consultations, and interviews will be used to collect information from both users and non-users.

Marketing

Marketing strategies during the first year included the launch of the project in several locations across Alberta, newsletter publications, presentations and publication of the User Manual. However, as the project developed more rapidly than expected and needs were identified that were not necessarily anticipated, it became apparent that marketing of HIA was not fully effective. Additionally, as regionalization of health in Alberta became fully operational, the context for health practice changed. To respond to these changing needs, an environmental scan was conducted to collect information for appropriate positioning of HIA and to plan how to better meet user needs in year two.
Environmental

As expressed above, HIA functions in an environment that is constantly changing. In order to respond to these needs and the exploding field of information development and distribution, an environmental scan was conducted.

The purpose of the environmental scan was to determine present and potential capacity to access and use HIA, including technical and telecommunications capacity, patterns and practices of use of HIA, and barriers and supports for access and use. Information was collected by means of survey, interviews and on-site visits.

Stakeholders for HIA include practitioners, program planners, funders and researchers in health promotion and disease/injury prevention. However, for the present, the environmental scan included staff in Regional Health Authorities (RHAs), the Alberta Cancer Board (ACB) and the Provincial Mental Health Board (PMHB). It is hoped that the survey can be expanded to include other groups in future.

Results

The vast majority (97%) of those surveyed have access to a computer, either at work or at home. Computers were most often used for word processing or email (mostly local area networking), and users rated their skill levels as fair, good or excellent. Sixty five percent of respondents with regular access to computers had signed on to the Internet at least once, and only 23% of respondents were regular Internet users. Barriers to Internet use included time, equipment, money and training.

The detailed findings of the environmental scan are currently being analyzed and will be discussed at the ITCH conference regarding their implications for HIA.

What Opportunities Exist in Future

The goals for year two are to increase the number of users, expand the content of the database, and increase sustainability of the project through a broadening of the funding base.

There have been many requests for website features that were not anticipated in the initial planning of the project, including on-line discussion groups (list-serve and newsgroups), website development, and residence of other public, professional and private groups or individuals on the HIA website. Progress has been made in planning to meet some of these needs.

Several of these strategies have the potential to generate funds and to reduce the costs of operating the project. These include, though are not limited to, website space and development, list serve subscription fees, corporate sponsors and advertising. Although our primary focus is publicly funded health promotion programs and research, there are requests to include private and commercial initiatives and information. These can be a significant source of funding and sustainability for the HIA project. During year two, HIA will further consider this market and will develop an appropriate definition of “commercial” and “private.”

Considerable planning is necessary to develop an appropriate and comprehensive funding strategy for future sustainability of HIA. The results of the environmental scan will be used to improve the quality of the Website and to enhance its attractiveness to potential funders, thereby securing future sustainability of HIA.

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Community Health Information Systems - 1

Chair: Paul Fisher
Enhancing Community Development Through A Collaborative Community Profile Database

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Keywords: Arthritis; Community Health Informatics; Community Development

Abstract

The Arthritis Society embarked on a community development project to support our strategic plan by redefining our regional structure to correspond with Ministry of Health regional structure. This was in response to the province's health care reform activities.

Our intent was to provide direction to our volunteer community groups on how to work locally within the changing health care system; we wanted to develop community profiles to evaluate existing services for people with arthritis in BC.

Our first step was to define the attributes of an ideal community for people with arthritis. These attributes guided the design and development of a database to support the development of community, regional and provincial profiles.

Data collected includes patient and general population demographics, prevalence of arthritis, community and The Arthritis Society resources and fund-raising information, organised by community, local health area and region throughout the province of BC.

The Community Profile Database is currently being used to plan services provided by the Arthritis Society across the province. We are working with our volunteer community groups to develop detailed community profiles. This activity will assist these groups in their work with local community health councils and regional health boards to plan and provide appropriate services for people affected by arthritis in BC.

1.0 Introduction

Arthritis and related disorders are the leading causes of disability in Canada. Of the four million people who live with arthritis, 600,000 are severely disabled by it. With our ageing population, that figure is expected to double over the next 20 years.

The Arthritis Society is a national charitable organization dedicated to helping people affected by arthritis. The B.C. and Yukon Division promotes and provides arthritis treatment, education and research. It operates 4 regional centres and hundreds of community-based treatment, self-management, exercise, volunteer and other outreach programs.
In response to a changing health care and volunteer environment, The Arthritis Society, BC and Yukon Division embarked on a Community Development Process. The project is intended to support the organization’s strategic plan and directions by:

- providing direction to volunteer network on how to work locally with the changing health care system
- establishing a way to recognize and support the volunteers of the organization
- redefining the organization’s regional structure so it corresponds with the Ministry of Health regions and community health councils
- developing community profiles that describe the existing services, distribution of people with arthritis and some indications of their needs
- meet the public’s demand for good stewardship for spending of donor dollars
- establish accountability of the division to TAS community groups
- establish accountability of TAS community groups to the division
- better meet the needs of people with arthritis in communities across B.C. and Yukon

2.0 The Steps of the Community Development Project

2.1. Define “ideal community for people with arthritis”

Based on research, volunteer and staff input, attributes of an arthritis-friendly community were developed. The health of people with arthritis is influenced by many factors in addition to the health care system. The degree of control that people with arthritis have over their lives, their coping skills and their capacity to make good choices strongly influence their health.

The following provides a brief overview of the key attributes desired in a community to better meet the needs of people with arthritis. Although the factors are listed separately, they work together in an interrelated way to influence health.

**Socioeconomics**
- Access to adequate income, since higher incomes and social status are linked to better health and unemployment is associated with poorer health;
- Control over work circumstances and workplace social support contribute to health;
- Support from families, friends and community members is associated with better health.

**Recreation**
- Access to appropriate and affordable recreation programs improves quality of life and expands social support networks.

**Safety and Physical Environment**
- Provision of physical security, accessible and affordable housing, and accessible public buildings and areas as well as promotion of respectful attitudes and behaviours create a quality of life that positively affects health.

**Lifelong Learning**
- Education for children and youth, and lifelong learning for adults are key contributors to health. Education equips people with the knowledge and skills for problem solving and helps to provide a sense of identity and control life circumstances. It improves people’s ability to access and understand information and make choices to keep them well.
Transportation
- Provision of accessible and affordable transportation and parking supports the independence of people with functional limitations.

Politics and Government
- Ability to advocate for people with arthritis to political bodies making policy and program decisions that influence social, economic and physical factors affecting health.

Health and Social Services
- Access to appropriate and effective health care services when needed;
- Greater emphasis on health promotion and independence.

Communications
- Access to appropriate information via media in languages that are culturally appropriate.

These attributes can be influenced at community, regional and provincial levels. A more detailed description of services and how they contribute to the model of arthritis-friendly community is available from the authors.

2.2 Develop a community profile database

A computer database was developed to collect information to assist in health needs assessment and planning based on the attributes of an ideal community for people with arthritis. The database was structured around the B.C. Ministry of Health’s boundaries of local health areas, health regions and regional co-ordination areas. Further breakdown of data by community was developed using postal codes linked to the local health areas.

Data was collected and/or imported from the following sources:
- BC Stats: Population Projections (1)
- prevalence of arthritis (2)
- TAS program statistics and information including:
  - clinical treatment
  - education and outreach
  - fund raising
  - volunteer network
- other community resources including:
  - physicians
  - allied health professionals
  - recreation facilities
  - support groups
  - seniors centres
  - wellness centres
  - child development centres
  - government agencies

The flexible design of the database enables extensive easy inquiry and reporting, using a combination of any of these variables based on community, regional or divisional breakdown. Summary or detailed information can be generated for any level of data.
2.3 Data Analysis

The community profile database is being used to identify the distribution of TAS and other arthritis-related services in comparison to the model of arthritis-friendly community.

2.4 Action Planning

The database is a useful tool for managers, program co-ordinators and volunteers working with other community agencies to plan and restructure services for people with arthritis in BC.

REFERENCES:


Moving From Hospital To Community: Impact of Patient Care Information Systems on the Delivery of Health Care Services

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Keywords: patient care information systems, impact

Abstract

A framework for evaluation of the impact of patient care information systems (PCIS) in health care services is discussed. The framework is based on two premises: (1) measures of impact in health care must include effect on the practice of health care professionals and patient outcomes. A well known quality of care model provides this base with the dimensions of structure (the human and organizational resources to support quality of care), process of care and patient outcome. (2) impact is not a static concept but changes over time as the technology evolves and users become more sophisticated. Hence the quality of care dimensions are applied to three levels of impact: automating manual tasks, automating processes or procedures, and supporting new capabilities. This framework's utility is illustrated in the assessment of PCIS impact in five community hospitals. General areas of impact that are identified include: efficiency and productivity, role/responsibility changes, "visible" accountability, and use of electronic communication. Potential applications of the framework to community health information systems are suggested.

1.0 Introduction

Patient care information systems (PCIS) have the potential to significantly improve health care delivery during periods of fiscal constraint, but have often failed to achieve the desired impact. Investment in information technology represents an opportunity cost and requires a commitment in money, time and energy. Therefore, emphasis has been placed on selecting the right system, training and implementation strategies. However, evaluation of impact must go beyond operational efficiencies and take into account how the computer technology is used as well as the social and behavioral processes that affect and are affected by its introduction into the practice setting [1]. Until the relationship between use and impact is understood, simply introducing more training and technology will not produce the desired impact. Without this understanding, as hospitals expand their use of PCIS into the community and community health information systems develop, the situation will remain unchanged.

2.0 Background and Research Questions

Many systems fail, not because of defects in the technology, but because of user resistance [2]. Development efforts focus on 'user friendliness,' believing that if a technology is easy to use and useful, it will be used and have a positive effect on performance [3]. The focus of many empirical and descriptive studies in health care has been on the selection and development processes that ensure system and information quality; on user training and involvement in the implementation process; the satisfaction of users and predicting system use [4-8].

However, it is not clear how these factors contribute to overall impact of a PCIS, both for health care professionals and the organization as a whole. Measures of economic benefits and organizational efficiencies are only part of this picture. Effect on the worklife of individual users, including their perceptions of changes in decision-making, control, productivity, social interaction, job enhancement and work environment, with resulting changes in patient outcome must also play an important role in determining impact of the technology.
The research problem in this study was to construct an analytic framework that would reflect the impact of PCIS on health care professionals and patient care. Two questions guided the study:

- What, if any, is the perceived difference in impact of PCIS on health care professional groups in hospitals?
- What factors explain such differences in impact among these groups?

The concept of impact in the study framework was based on Donabedian's quality assurance model and his three measures of quality: structure, process and outcome [9-12]. In addition, impact is not a static concept, but must take into account the increasing sophistication of the technology and its users. For this reason, Donabedian's measures were examined for each participant group, at three levels of impact for information technology: substitution, proceduralization, and new capabilities [13] (Figure 1).

### Figure 1 - Analytic Framework

![Analytic Framework Diagram](image)

#### 3.0 Research Method and Analysis

A field study was conducted in five community-based acute care hospitals in British Columbia. These were selected from hospitals with a minimum of 120 beds and operational PCIS, ranging from (1) extensive systems to (5) minimal systems. Extended or continuing care facilities and teaching hospitals were excluded from the study because their information needs, funding and complexity differed substantially from the acute care facilities.

Four health care professional groups participated in the study: nurses, pharmacists, laboratory technologists and physicians. Based on a literature review, fifty semi-structured interview questions were developed. These were reviewed by provincial "content experts" representing each of the four groups, then revised and pilot tested. Data were collected through eighty-five semi-structured interviews with individual participants having varying levels of computer experience, observations of the use of PCIS and review of written archival documentation relevant to the adoption and use of PCIS in each organization. Data were analyzed manually and with the assistance of a textbase manager called Folio VIEWS (3.1 for Windows [14]).

#### 4.0 Findings: Impact of PCIS Across Hospitals and Groups

The perceptions of PCIS impact were analyzed for each group in each hospital using the analytic framework (Figure 2). The study hospitals differ on one important variable: the extent of PCIS implementation. As expected, Hospitals 1 and 2 demonstrate more evidence of impact in structure measures at levels 1 and 2 for all groups. However, they are not necessarily able to identify how expected linkages between measures of structure, process and outcome occur. Hospitals 4 and 5 do not demonstrate this same level of impact, but unexpectedly are able to identify specific linkages. For example, one Surgical Admission Program demonstrates use of their PCIS to streamline the patient admission process and to provide pre-operative teaching and anesthetic assessments in ways that reduce length of stay, as well as increase patient satisfaction. Five themes illustrate these differences with respect to the impact of PCIS use.
4.1 Increased Efficiencies and Productivity

Automating manual clerical tasks (structure) is one of the primary reasons for implementing a PCIS. Laboratory technologists and pharmacists are more affected by this change, which is intended to support quality patient care (process). In contrast to the prediction that computers free up time to spend with patients, users feel they have less time. This is because the number of staff remain the same, but they are also able to complete more tasks and the acuity of patients is increasing. For example, increased efficiency translates into patients spending less time waiting in outpatient labs. A receptionist completes the requisition quickly and efficiently before the blood is drawn. The lab technologist can move quickly from one patient to the next, but has little time for personal contact, answering questions or monitoring the puncture site. Pharmacists also report a decrease in job satisfaction due to the increased time spent in front of a terminal versus interacting with patients and other professionals. Medication orders are often faxed to the Pharmacy Department, followed by lengthy data entry sessions (similar to the "intellectual assembly line" described in other industries).

4.2 Role and Responsibility Changes

The well defined roles and responsibilities of health care professionals may change as automation blurs the distinctions between structure and process. These changes are experienced primarily by nurses and physicians, as changes in process (e.g., patient-care decisions) are expected to occur as a result of changes in structure (e.g., faster lab results). For many participants the computer provides more timely information, but whether their actual decisions change is not clear.

Role changes also occur when technology is used by one group to accomplish tasks formerly completed manually by another group. For example, unit secretaries transcribe physicians' hand written orders onto paper requisitions, which are then sent to the appropriate department. Nurses are responsible for ensuring this is done correctly and the results forwarded to physicians as needed. When physicians or nurses enter orders directly into the computer, all three roles change. Study participants are unable to identify specifically how they expect these changes to unfold.

4.3 "Visible" Accountability

Changes in professional roles also result when scrutiny of professional decisions and actions becomes possible through integrated PCIS. This change is experienced by all four groups, but occurs primarily in measures of structure for lab technologists and pharmacists. Automating tasks such as reporting results or medication profiles creates an electronic audit trail documenting the volume and accuracy of work accomplished (e.g., the number of orders processed, number of errors). In the manual system lost requisitions plague both Nursing and ancillary departments, often meaning delays in patient care decisions. It is difficult to identify who made an error and this creates an organizational dynamic with whole departments or units deemed by others as being "incompetent" and
always losing or not completing requisitions correctly. Use of the PCIS creates opportunities to identify individuals who have incorrectly completed requests, collected specimens or entered results and take corrective action.

For nurses and physicians, this change occurs primarily in process measures such as patient-care decisions that are recorded and immediately available for inspection by other professional groups. Prior to use of a PCIS, decisions, use of resources and certain aspects of patient care are often "invisible." They are known by the individual practitioner and are expected to occur as part of a professional practice. With the use of PCIS, this information becomes available for scrutiny within one's own department or peer group, as well as across departments. For example, it becomes easier for both Nursing and the Laboratory to identify potentially inappropriate orders and for pharmacists to make suggestions for drug administration.

4.4 Extensive Use of Electronic Communication

Users feel tremendous time savings occur through electronic messages taking the place of notes, memos, notices, and "telephone tag." Guidelines for "appropriate use" of previous communication tools were never formally established and this new form of electronic communication is often used without rules. However, its effects are much farther reaching than in the past, altering established communication patterns and norms. In particular, changes occur with respect to the access that subordinates have to managers and vice versa. Related to this is the fact that an audit trail of all communication is kept. Therefore, both the sender of a message promising to take action, as well as the receiver of a message can be held accountable. "I didn't get the message," is no longer a valid excuse for inaction.

An area of particular concern for healthcare professionals is the potential of electronic communication to create a feeling of distance between a user and the "real world," whether that be patients or staff. For example, physicians having access to results from home or office reduces the necessity of returning to the hospital to review results. As well, being able to combine clinical information in new ways (e.g., through graphics), also has the effect of removing the clinician one step away from the original source of patient information. In the Lab the sense of "connecting with the patients" is lost when it becomes more efficient to match bar code labels to specimens and requisitions. Although using patients' names may be less efficient, it provides a way to follow their progress and recovery. In Pharmacy, orders are processed rapidly as they are received, without the opportunity to immediately follow-up on issues or questions that arise. These are forwarded to other pharmacists assigned to clinical duties, creating a fragmented picture of the patient's medications and their care.

5.0 Potential Applications to Community Health Information Systems

A similar pattern of impact is evolving as PCIS applications extend from acute care facilities into the community and Community Health Information Systems (CHIS) mature. Emphasis remains on computer technology selection and development to achieve health system efficiencies and on training to develop proficient users. However, applications relevant to patient care are no longer limited to single systems, but may include many combinations of access to independent sites on the Internet or development of local Intranets where information is shared by a group of users. This reinforces the concern of healthcare professionals in maintaining a connection between their source of data (the patient) and their tasks or decisions related to patients.

The technology allows information to move faster and makes it more accessible (i.e., structure changes), but there remains little evidence how these changes can, or will, be integrated into the process of care or how patient outcomes change. Electronic communication of information between healthcare agencies and providers may take place "at the speed of light," but they must be accompanied by demonstrable changes in the behavior of providers and caregivers for patient outcome to change. For example, the impact of e-mail may be strictly on efficiency when the manager is unable to fill a request for a bed in a community facility any faster with an electronic or paper request. A healthcare organization notes that it has "put a PC on the desk of each of its 1,000 physicians and uses the Internet to disseminate clinical guidelines instantly" [15]. Vast amounts of information are available and accessible, but it is unclear what evidence will demonstrate how this translates into process changes (e.g., physician practices) or patient outcomes.
6.0 Conclusion

There is a perception that additional clinical information systems are needed before an impact in health care will be achieved. This study suggests the necessity for understanding the link between use and impact before proceeding with more systems and the development of a framework to guide future research. Implementing PCIS has often been justified on an economic basis, to aid in reducing errors and length of patient stay, or to support "better" decisions related to patient outcomes. It remains unclear how more timely and efficient movement of information around the organization translates into changes in behavior. Users feel these changes must be happening, although cannot identify supporting evidence.

Computerization provides the opportunity to automate certain tasks, thereby making underlying processes of the organization known [16]. Accountability becomes an important issue as the previously "hidden" work of professionals becomes "visible" and therefore available for scrutiny. Long standing roles and responsibilities of health care professionals change, and managing these areas of impact may provide an important key to increasing the value of investments in PCIS.

For PCIS to have the expected impact, whether in an acute care organization or in the community, there must be a clear understanding of two areas:
- how changes in structure (e.g. automating tasks) will translate into changes in process (e.g. making decisions) and outcome (e.g. patient satisfaction or length of hospital stay);
- what evidence will demonstrate these changes have occurred.

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7.0 References


Evaluating Primary Health Care Software Packages

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Keywords: Software Evaluation, Primary Health Care, Software Packages

Abstract

Nurses providing Primary Health Care (PHC) services from stationary and mobile clinics have an excessive administration burden. Information technology can play a major role in alleviating this administrative task. Health managers who must make the decision to purchase a specific computer system, are not qualified IT experts and are not in the position to make the best choice. This is where software evaluation techniques can be of tremendous help.

This paper will report on the work done by a task group to evaluate two software packages for PHC. A stepwise approach was followed to do the evaluation. In this process a software evaluation tool was developed and tested in the field.

1.0 Introduction

The health services of the Republic of South Africa are hampered by an excessive administration burden [1]. They have, therefore, embarked on a process of computerization. This is evidenced by the national tender for the computerization of the national health information system which is in the process of being granted. Even though all provincial health departments will have to comply with the national decision of the computer system to implement, it is, however, expected that the full implementation of all software and hardware of the proposed system is still a couple of years away. There are, therefore, still many lessons to be learned in the meantime and time to make a contribution as to what the eventual system should look like.

To obtain insight into what nurses require of a computer system for providing PHC from clinics, a task group was established in the Free State (a province in the Republic of South Africa) to evaluate suitable PHC software packages. The lessons to be learned from this endeavor would be used as requirements that the eventual system must meet.

Software evaluation as used for the purposes of this paper is defined as: the process through which health care providers determine by means of quantitative results whether one or more of the available software packages are suitable for the computerization of PHC services. If several packages are suitable, software evaluation will further select the “best” one [2].

2.0 Methods

The following seven steps were followed in the evaluation process [3].
2.1 Determine the objectives that the computer system must meet

The task group included representatives of all levels of the health services who had a detailed knowledge of the happenings in the field. A computer expert was also part of the task group. At their first meeting the attendees had a brainstorming session to determine exactly what they expected from a computerized system for PHC. This was an opportunity for each one to present his wish-list of what the computer program must do for him. This information was very important, for the evaluation instrument had to measure whether the software packages fulfilled these requirements. Some of the objectives identified in this manner were:

- The system must be user-friendly.
- The system must have a comprehensive patient record.
- The system must cater for all PHC functions.
- The system must save time - make nurses more productive.
- The system must provide management information.

2.2 Determine the sample

At the same meeting, the nurses to participate in the evaluation were also selected. Care was taken that all six regions of the province were represented and that each region had at least one participant from management, one from mobile clinic services and one from stationary clinic services. A larger sample would have been preferred, but because of the costs involved (for training, traveling, etc.) and the fact that the nurses will have to do extra work (the old manual system had to be maintained while the computer system was tested), the study had to make do with a small sample. In the end 26 nurses took part in the evaluation.

2.3 Identify potential software packages to evaluate

A market survey revealed four software packages that were specifically designed for application in PHC clinics. Several hospital information systems that could be scaled down to clinic level were also identified, but they did not meet the requirements of the clinics satisfactorily.

2.4 Determine the procedure to follow

The task group members decided that two packages should be tested in the field for approximately two months. Two packages had, therefore, to be selected from four available packages. It was decided that the vendors of the particular programs should demonstrate their products to the task group. On the basis of the demonstration and a few other criteria, two packages would then be selected.

The task group had consensus, after the demonstrations by the vendors, that the presentations and the products of two of the vendors stood out. These products have already been implemented in several clinics throughout the country and have undergone several revisions. It was, therefore, decided that the chosen two packages, call them A and B, were to be field tested for two months in the province.

It was not possible for each nurse taking part in the study to test both the programs, the reasons being the time and costs involved. Only two nurses were able to test both programs. The rest of the nurses only tested one program. Both programs were tested in all the regions but either in a mobile clinic or a stationary clinic setting.

2.5 Establish training sessions

A two-day training session for each package was arranged. Fourteen nurses attended the training session for package A and twelve nurses attended the training for package B.
Valuable lessons were learned during the training. For most of the nurses who attended the training, it was their first exposure to working on a computer by themselves. This meant that the first couple of training sessions were just basic computer skills - how to use the keyboard and mouse, how to work in the windows environment, etc. The nurses were also overwhelmed by the many different functions, screens and buttons of the programs. If they moved onto a new function before they were proficient in the previous one, they forgot how it worked. It seemed that training sessions should be incremental. By this is meant that, rather than having one training session of a couple of days, several short training sessions should be instituted during which only one or two new concepts are learned. The nurses can then go back to their clinics and practice these concepts in the field.

2.6 Establish an evaluation instrument

Simultaneously with the process described above, an evaluation instrument was designed. A first version of the instrument was discussed at the first task group meeting. Because the nurses had no exposure to PHC computer programs at that stage, few comments were received. A second version was completed after one of the training sessions. From the results it was clear that they did not understand some of the questions and that they did not fully understand the computer program. What was learned from this was that the questions on the instrument must be in very simple terms and even then each question must be clearly explained in order that the nurses understand the same thing.

2.7 Do the evaluation

The final evaluation of the software packages took place after the packages were field tested for two months. Before the evaluation, a sharing of the experiences gained during the project was done by the participants. It was important that all lessons be learned so that the eventual transition to a computerized system will be as smooth as possible. The feedback received from the nurses can be summarized as follows:

Training

- A basic computer literacy course must be done first of all.
- Regular courses at different levels must be provided so that nurses can progress at their own tempo.
- After a course, the nurse must go back to the clinic and practice what she has learned.
- Support must be available if the nurse cannot continue.
- Some means must be established to monitor that the nurses apply what was taught to them in the training sessions.
- The manual system should not be replaced by the computer system before the nurses are fully trained in the utilization of the whole program.

The Program

- There are too many screens - more information on one screen is required.
- It takes too much time to move from one screen (baby card) to the next (ante-natal) for a specific patient.
- The program must be scaled down - too much unnecessary information is required.
- It is time-consuming to capture the data (30 minutes per patient). The computer program is slower than the manual system. Less patients will be seen per day. The computer system will not work in a busy clinic.
- Several bugs still exist in the programs.
- The computer will have an effect on the nurse-patient relationship.
- It is very time-consuming to put the existing patients on the system - populate the database.
- The mobile clinics are not fitted with battery chargers for the notebooks.
- Too much information is required - the same as the existing paper-based system.
• The programs, as they are now, are more difficult to work than the manual system.

The evaluation instrument was then studied to ensure that all questions were relevant and understandable. Questions relating to output and queries were omitted, because the programs were not used for those purposes. Some questions relating to the dataset were added. The instrument specifically evaluated the data-capturing aspect. The management functions of the programs were not used at all and were, therefore, not evaluated. An example of the instrument is attached as Appendix A.

After consensus was reached on the questions of the evaluation instrument, a decision had to be taken on the importance of the various questions. One way to do that was to give each question a different weight. Because of the number of questions, this presented a difficult task. The meeting, therefore, decided that each nurse should indicate the importance of each question, by giving it a weight of 1, 2 or 3. The higher the number, the more important the question. The nurses responded overwhelmingly with a weight of three for nearly each question and consequently all the questions were considered as equally important.

3.0 Results

Only two nurses evaluated both programs. Those nurses who evaluated only one program, had a problem in the sense of what to compare their program to. To test if their evaluation was meaningful, their results were compared to that of the two nurses who had used all three programs. A one-way analysis of variance was done between the two groups (those who tested all programs and those who tested only one program). For program A the answer to only one question was significantly different at a 0.01 level of significance. For program B no questions differed significantly. Even though the samples were terribly small, this gave the indication that the absence of a program for comparison purposes, had little effect on the evaluation results.

The results of the evaluations are displayed in Table 1.

Table 1: Mean values for each question

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>PROGRAM</th>
<th>PROGRAM A (N = 10)</th>
<th>PROGRAM B (N = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1</td>
<td>3.000</td>
<td>3.857</td>
<td></td>
</tr>
<tr>
<td>Question 2</td>
<td>3.600</td>
<td>3.857</td>
<td></td>
</tr>
<tr>
<td>Question 3</td>
<td>3.200</td>
<td>2.286</td>
<td></td>
</tr>
<tr>
<td>Question 4</td>
<td>3.400</td>
<td>3.286</td>
<td></td>
</tr>
<tr>
<td>Question 5</td>
<td>3.800</td>
<td>4.000</td>
<td></td>
</tr>
<tr>
<td>Question 6</td>
<td>3.200</td>
<td>3.571</td>
<td></td>
</tr>
<tr>
<td>Question 7</td>
<td>3.800</td>
<td>3.429</td>
<td></td>
</tr>
<tr>
<td>Question 8</td>
<td>4.000</td>
<td>1.143</td>
<td></td>
</tr>
<tr>
<td>Question 9</td>
<td>3.100</td>
<td>3.429</td>
<td></td>
</tr>
<tr>
<td>Question 10</td>
<td>3.200</td>
<td>3.429</td>
<td></td>
</tr>
<tr>
<td>Question 11</td>
<td>3.200</td>
<td>4.000</td>
<td></td>
</tr>
<tr>
<td>Question 12</td>
<td>3.400</td>
<td>3.857</td>
<td></td>
</tr>
<tr>
<td>Question 13</td>
<td>3.100</td>
<td>4.000</td>
<td></td>
</tr>
<tr>
<td>Question 14</td>
<td>2.300</td>
<td>3.571</td>
<td></td>
</tr>
<tr>
<td>Question 15</td>
<td>3.800</td>
<td>3.000</td>
<td></td>
</tr>
<tr>
<td>Question 16</td>
<td>3.700</td>
<td>1.571</td>
<td></td>
</tr>
<tr>
<td>Question 17</td>
<td>3.300</td>
<td>3.000</td>
<td></td>
</tr>
<tr>
<td>Question 18</td>
<td>3.100</td>
<td>2.714</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>60.2</td>
<td>58.0</td>
<td></td>
</tr>
</tbody>
</table>
All the questions were phrased in a manner that the higher the value, the better the evaluation. A reasonable approach to distinguish between the two programs, was to look at the total mean values. This would lead to a conclusion that package A was rated higher than package B by the evaluators. A closer inspection of the mean values, however, revealed that for 10 of the 18 mean values, package B was higher than package A. In reality the difference in total values was mainly due to three questions, Questions 3, 8 and 16. Question 3 measured the comprehensiveness of the program. Question 8 measured the quality of the paper documentation and Question 16 the training and support provided. This was a true reflection of the programs, because program B did not contain all the modules, provided no paper documentation and their training and after training support was of a poor standard. These problems are all easy to rectify though. For the questions relating to the ease of use, user-friendliness, and ease of learning program B performed better than program A. Especially in the case of Question 14, the interference of the program in the nurse-patient interaction, program B evaluated significantly higher. In the opinion of most users these are the more important indicators. From Table 1 it can be seen that a one-way analysis of variance showed significant differences, on a .01 level of significance, between Questions 3, 8, 14 and 16 only.

4.0 Conclusion

Valuable lessons have been learned during the whole process of evaluating PHC software packages. Several nurses became involved in the whole process of computerization. Each minute that they spent in front of the computer, either through training or working with the program, was an investment for the future. The nurses have learned, through this experience, what to expect of a computer program for PHC.

Several pitfalls in the training process have been identified and suggestions to rectify them have been made, the most important being that the training should be spread out over longer periods of time and should be on a module-by-module basis. The first module should be a basic computer skills module. After each module the nurses should first apply what they have learned before they continue with the next module.

Several errors and discrepancies in the programs have also been identified, the major ones being that the programs are too complicated and take too much time to capture the data. There is a clear indication that programs which are easier to use and requiring less data, should be investigated as a matter of urgency.

An evaluation instrument was developed and tested on two software packages. Even though all the nurses could not test both programs and the sample sizes were small, valuable results have been obtained. One overall measure is dangerous and should be used with caution. The computer programs are in certain aspects stronger and in others weaker. Some of the shortcomings can easily be rectified, others are more difficult to change. The questions on the evaluation instrument should, therefore, be considered individually and higher weight should be given to the more important questions. If ease-of-use is really important, then it would appear that program B evaluated better than program A. This is irrespective of the fact that program A had a higher overall value.

5.0 References


APPENDIX A

SOFTWARE EVALUATION INSTRUMENT

Data Capturing Facilities

Software Package: ________________________________

Overall how would you rate this software package in terms of the following:
(1 = non-existent, 2 = poor, 3 = fair, 4 = good, 5 = excellent)

<table>
<thead>
<tr>
<th>Weight</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The task to register a new patient is easy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. There are convenient means to search for a patient.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. The computer program provides for all PHC services.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. The computer screens correspond closely to the old (manual)way of doing things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. It is easy to find what I need to do in the program.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. The amount of typing I need to do is minimal.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. The quality of the on-line help is ....</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. The quality of the paper documentation is ....</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. The interaction with the system is clear and understandable ....</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. My productivity will increase by using the program.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. I find the computer program very easy to use.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. It was easy to learn to use the computer program.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I never have to wait for the computer while it is busy with processing.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. The capturing of data with the computer minimally interferes with the patient interaction.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. This computer program is ideal for the computerization of PHC services.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. The training and after training support was good.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. The dataset is comprehensive and provides for all prescribed routine data.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. The clinical patient record is comprehensive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The B.C. Health Information Standards Council

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Keywords: Standards, Information Systems, Information Sharing, Computer Networks

1.0 Overview of B.C. Health Information Standards Council

The British Columbia (B.C.) Ministry of Health, in consultation with a broad range of health sector representatives, identified a priority need for the establishment of a B.C. Health Information Standards Council as one of the strategies that will help enable and facilitate information sharing within the health system.

The role of the Council focuses on the identification of standards and guidelines which promote effective and efficient health information sharing.

The client and patient benefits that should be realized will be greater protection of privacy while allowing multiple health record access, cost savings, improved delivery of services and programs, province-wide integration of health information systems, and better health through enhanced research.

The Council is composed of an informed, experienced group of health system representatives (please see Appendix A) who advise the Ministry of Health on health information standards that should be adopted across the province. Membership on the Information Standards Council is voluntary and the number of members has been limited to facilitate discussion and decision-making. Council members represent direct-users of information in the health sector.

The Health Information Standards Council maintains direct on-going links with the Canadian Institute for Health Information (CIHI) by direct liaison, active participation in national projects, and participation of Council Members on CIHI’s national board to manage the Institution.

The Health Information Standards Council has met monthly since its inception in October 1995. Since then it has established a regular format, site and process for its meetings, developed and approved its Terms of Reference (please see Appendix B), and established a review process for standards. The Council has developed a set of key operating principles (please see Appendix C), along with a philosophical framework or model for this review.

In addition, it has set criteria for establishing task forces and appointing people to them, and has documented a list of major stake-holders who will be invited to comment on the feasibility of standards implementation and utilization.

Recommendations have been made to the Ministry of Health and approval received for B.C.’s first health information standard... the Personal Health Number or PHN... along with interim guidelines for the safety and security of health information systems (COACH - "Security and Privacy Guidelines for Health Information Systems - 1995"). The Council recently recommended HealthNet/BC’s connection layer standard TCP/IP (Transmission Control Protocol/Internet Protocol) to the Ministry of Health as the next formal health information standard for the province. This standard has now been approved by the Ministry.

A Communication Plan has been prepared. It includes an information brochure, list of relevant interest and stakeholder groups, the sharing of its Minutes of meetings with the Coordinating Council, an information package on the Council itself, and the beginnings of an information web-site on the Internet.
The plan also includes communicating with Council members by electronic mail and being able to send its minutes, agendas and other documents to members using this media. Further, the plan provides for the availability of speakers to provide information to organizations or groups about health information standards and about the Council.

The Ministry of Health has appointed a full time Coordinator (Jim Coward) to provide the Council with professional and organizational support.

As a relatively new organization the Council is aware of both the potential positive and negative implementation effects that may occur if a health information standard is recommended. It was necessary for the Council to develop, and continue to maintain, excellent communications with major stake-holders in the health system, public or private.

The B.C. Health Information Standards Council has a limited budget and few technical experts among its members. The Council needs the support of private and public organizations to provide this expertise when dealing with particularly complex issues.

The size of the task of identifying, reviewing and recommending health information standards is huge. The Council continues to be aware that it is not that there are no standards in use, it is that there are thousands!

Early work of the Health Information Standards Council was aimed at developing an administrative, organizational and philosophical base from which to carry out the identification and review of health information standards. This has been accomplished.

The next steps for the Council will be to continue to review and recommend health information standards to the Ministry of Health and to meet with their colleagues on the Health Information Management Coordinating Council to gain a better understanding of both common and regional priorities. It will continue to develop the "Health Information Standards" manual for eventual distribution to interested parties and establish a clearing house for information about standards.

The Council is currently reviewing the "Client Registry" to determine if it should be recommend as an information standard. Also, it is planning to review MIS/Financial Health Information Standards, Clinical Classification & Vocabulary Codes and Provider/Facility/Location Unique Identifier Codes in the near future.

In addition, the Health Information Standards Council will begin to increase its activities in providing information to interested persons about health information standards in B.C., plus, move towards developing an accepted accreditation and certification process that is supported by the stake-holders in the system.

Work has begun on meeting the goals and objectives that will provide the client, patient, provide and institution with the benefits being sought.

1.1. Additional Information Sources

Further Information: For additional information please contact the Coordinator (Jim Coward) via the telephone, fax or email addresses given below. The Internet web site may be viewed at:

http://www.hlth.gov.bc.ca/hlthinfo/process/stdscl/stds.html
2. Appendices

2.1. Appendix A

B.C. Health Information Standards Council

MEMBERSHIP LIST: (As of September 1, 1996)

Chair: Mr. Bob Cronin
Assistant Deputy Minister
Corporate Programs
B.C. Ministry of Health

ex-officio: Mr. Dick Alvarez
Senior Vice-President
Canadian Institute for Health Information (CIHI)

Two-Year Membership Appointments - Conclude August 31, 1997

Dr. Joanna Bates
Director, Medical Education
St. Paul's Hospital

Ms. Pat Coward
President & CEO
Greater Victoria Hospital Society

Mr. Chris Mazurkewich
Vice-President, Finance & Administration
Kelowna General Hospital

Professor Denis Protti
School of Health Information Science
University of Victoria

Mr. Roger Turner
Director, Public Education
Comcare (Canada) Ltd.

Two-Year Membership Appointments - Conclude August 31, 1998

Dr. Alan Askey
College of Physicians
and Surgeons of B.C.

Ms. Judy Cameron, Administrator
Slocan Community Hospital and Health Care Centre

Ms. Susan Downey
Manager, Finance & Administration
Peace River Health Unit

Ms. Betty Lee Moore
Director of Finance
B.C. Rehabilitation Society

Ms. Dora Nicinski
CEO - Upper Island/Central
Coast Regional Health Board

Ms. Melva Peters
PharmaNet Coordinator
College of Pharmacists of B.C.

Mr. Rick Roger
Vice-President, Finance & Administration
Vancouver Health Board

Dr. Ray Simkus
General Practitioner
B.C. Medical Association

Ministry of Health Appointments

Mr. Barry Gray, Executive Director
Systems Division, Ministry of Health
Liaison - Coordinating Council

Dr. Shaun Peck
Deputy Provincial Health Officer
Ministry of Health

Professional Support

Mr. Jim Coward, Coordinator
Health Information Standards Council
Systems Division, Ministry of Health
2.2. Appendix B: B.C. Health Information Standards Council

TERMS OF REFERENCE (Approved: November 20, 1995)

Introduction:

The intent of the Terms of Reference is to define the purpose, goals and major objectives, membership, role, and decision-making and reporting processes for the B.C. Health Information Standards Council.

Background:

The vision for Health Information Management in British Columbia is to effectively and efficiently manage information so as to support the health system. An integrated network, that connects participants and functions, is an integral component that will enable this process.

The establishment of a B.C. Health Information Standards Council is one of the strategies that will help enable and facilitate this vision. The standardization of data, applications and technology will facilitate secure information sharing within the health system.

Role:

The Council will focus on the identification of standards and guidelines which enable, facilitate and promote effective and efficient health information sharing. In most instances, this focus will result in standards and guidelines in the areas of data, applications, technology, security, confidentiality and privacy.

Note: The recommended focus and scope of the Council specifically excludes making decisions on what information should be shared within the health system. Those determinations will be made by health professionals, patients, etc. The focus of the Council will be on how information should be exchanged given the information sharing needs identified by information users; and

The Council does not impose or enforce the use of standards or guidelines.

Major Goals:

The major goals of the B.C. Health Information Standards Council will be to:

- Identify in what areas standards and guidelines are required;
- Review existing provincial, national and international standards and their applicability to B.C. issues. Where it is reasonable to do so, B.C. should adopt existing standards and guidelines;
- Seek the input of relevant interest groups as to the most appropriate and practical standards and guidelines to be adopted;
- Make recommendations to the Ministry of Health;
- Publish, promote and provide education related to health information standards and guidelines approved by the Ministry of Health;
- Act as a focal point and clearinghouse for provincial health information standards issues; and
- Ensure a process for certification and/or accreditation of products and services employing standards is implemented.
The Ministry of Health:

The B.C. Health Information Standards Council relationship to the Ministry of Health will be as follows:

- The Council will exist at the pleasure of the Ministry of Health and will be accountable to the Ministry of Health.
- The Council will make recommendations to the Executive Committee of the Ministry of Health regarding health information standards and guidelines appropriate for use within British Columbia.
- The Ministry of Health will have the responsibility to approve, mandate, promote and ensure the adherence to province-wide standards and guidelines.

Standards Council / Coordinating Council Relationship:

B.C.'s Health Information Standards Council and Health Information Management Coordinating Council work closely together in order to understand and support the role of each other in health information management. The Standards Council will focus on Standards that support information management priorities on the advice of the Coordinating Council. The Coordinating Council will support the Standards Council in the communication, acceptance, implementation and use of approved information standards in all regions of B.C.

Objectives:

The B.C. Health Information Standards Council will establish measurable objectives for the implementation of effective strategies and activities in order to achieve its goals.

Membership:

a. Membership: Council membership is voluntary and the number of members will be limited to facilitate discussion and decision-making.

b. Representation: Council members will represent direct users of information in the health sector. Members do not represent any organization and may not be vendors of products and services which are used in health information management.

c. Qualifications: Council members will hold senior positions within the health system and have a broad understanding of the administrative and clinical business issues facing the changing health system. Also, Council members will be recognized by their peers as leaders and innovators in terms of health information management.

d. Terms of Appointment: Members will be initially appointed for one or two year terms in order to provide for continuity of the Council. Members will thereafter be appointed for two-year terms. Members may be re-appointed.

e. Chair: The Council will be chaired, for the first six months, by Mr. Bob Cronin, Assistant Deputy Minister, Ministry of Health; thereafter, other arrangements may be made.

Council Meetings:

- The B.C. Health Information Standards Council shall meet on a regular basis, usually one day per month. Meeting locations will be determined by the Council.

- The Council will circulate an agenda prior to each meeting. An agenda may be altered by the Council.
Minutes will be kept of each meeting which are circulated to each member and specified staff of the Ministry of Health.

Council minutes and records shall be kept on file at the Ministry of Health.

Task Forces:

The Council may be supported by task forces or working groups as required. These groups will be named by the Council and can undertake detailed work on specific topics.

Task forces may include representation from direct users of information, organizations, and vendors of products and services and will usually be chaired by a member of the Council.

Task forces shall keep minutes and records of their activities. Task forces shall be disbanded when their work is concluded, as determined by the Council.

Decision-Making:

Decisions will be usually be made by the B.C. Health Information Standards Council using a consensus approach. When necessary the Council may decide to use other approaches (e.g. by voting, using problem solving techniques, submitting different option reports to the Ministry, etc.).

2.3. Appendix C  B.C. Health Information Standards Council

KEY OPERATING PRINCIPLES (Approved: January 19, 1996)

To support its goals the B.C. Health Information Standards Council has adopted the following Key Operational Principles:

1. Standards will be used across the health system
   Standards will support system-wide authorized information sharing.

2. Standards will support security, confidentiality and privacy
   Standards will facilitate personal health information being available only to those who need to know the information and are authorized to have the information.

3. Standards that are needed will be recommended
   Only standards that are required to support information sharing at all levels of the health system will be recommended.

4. Standards will support high quality information
   Standards will be recommended that support the collection and use of valid, reliable, and consistent information.

5. Standards will support cost-effectiveness
   Standards will support cost-effective information management.

6. Standards already accepted will be recommended
   Wherever appropriate standards will be recommended that are already generally accepted.
Internet Applications - 2

Chair: Jim Coward
Health Data Networks: The Central West Health Planning Information Network (CWHPIN)

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Keywords: community health, informatics, world wide web, Internet

Abstract

Current changes in the Canadian health care system promote the use of timely and relevant health information to determine the need for, design, implement and evaluate programs. The most efficient means of acquiring access to this type of information is through a health data network. The Ontario Ministry of Health recently has established a number of Health Intelligence Units (HIUs) throughout the province to address the information requirements of Health Units and District Health Councils. One of these, the Central West Health Planning Information Network (CWHPIN), has undertaken the development of an electronic communications network. This network provides its members with an opportunity to communicate with one another; participate in topical bulletin boards and discussion groups; access to both a textual and data library; and a web site on the Internet. This paper discusses the process by which the needs of the partners were assessed and a pilot network established, as well as the experiences of the users in identifying and creating applications. The results provide hints to those who themselves are considering the development of such networks.

1.0 Introduction

Decision makers and program providers working within the Canadian health care system are faced with the challenge of increasing efficiency to allow room for expenditure reductions while improving or maintaining the quality of health care available to the population. In response to this challenge, the Ontario Ministry of Health has created regional Health Intelligence Units (HIUs) to provide the Public Health Units and District Health Councils with a regional source of health data, information and intelligence. The concept of the HIU was first introduced by Kerr White in 1982 [1]. A detailed presentation on the proposed structure and goals of HIUs was presented at ITCH'94 in a paper by Spasoff, Chambers and Goodman [2]. In general terms, the goal of an HIU is to work in partnership with its Public Health Units, District Health Councils, and an Academic Health Science Centre, with support from the Ontario Ministry of Health, to make their programs more responsive to the needs of the population. The first HIU in Ontario, the Central West Health Planning Information Network (CWHPIN), began operation in the fall of 1995. At the first annual planning day of CWHPIN, the partners identified electronic connectivity as one of CWHPIN's priorities for 1996. This paper describes how CWHPIN responded to that priority and established an evolving electronic communications network for its partner Public Health Units and District Health Councils.

2. Development of an electronic communications network.

The first step was to identify the needs and existing capacity of the partners with respect to electronic connectivity. The second step involved the development of a technology acquisition plan that was focused enough to contribute to the network and yet flexible enough to provide some benefit to the varying capacities among partners. The third step was to offer training to staff at each partner to ensure that the technology provided could be utilized to access the electronic communications network. Concurrent to these steps, CWHPIN established a World Wide Web (WWW) site accessible throughout the Internet so that partners could both access and disseminate information once connected. These steps were selected so the CWHPIN electronic communications network could incorporate a Public Health Informatics approach rather than simply being a source of data. Public Health Informatics is the
science of applying Information Age Technology to serve the specialized needs of the community health by providing information and intelligence in addition to data [3].

2.1 Survey of partners to identify needs and capacities for electronic connectivity technology

Key informants from each partner were identified and surveyed via telephone. Respondents were asked several questions pertaining to the type and number of computers, modems, modem telephone lines, LAN connectivity, and Internet access available to staff. In addition, respondents were asked to determine what proportion of their organization were trained to use the Internet including e-mail and the world wide web. Although each partner was going to have at least one connection to the electronic communications network, the survey was also designed to collect information on how extensively the electronic communications network would be used by each partner. Respondents also were given the opportunity to identify ways in which the electronic communications network could best serve their needs.

2.2 Technology acquisition plan

Based on the data collected in the survey, the following four themes were identified: 1) that there was a broad range of technology and levels of expertise within and between CWHPIN's 15 partners; 2) the majority of CWHPIN partners did not have access to e-mail or the world wide web; 3) the majority of partners would benefit from staff training initiatives related to using electronic communications; and 4) several partners were in need of technological upgrades to utilize GUI based browsers. The required upgrades included faster modems and CPUs and increases in RAM. These four themes were used to develop a technology acquisition plan that would ensure all partners had a minimum level of technology and staff trained to utilize the electronic communications network. The technology acquisition plan was approved by the CWHPIN steering committee and the Ontario Ministry of Health.

2.3 Equipment acquisitions

The technology acquisition plan allocated resources to ensure each partner could achieve a minimum level of electronic connectivity. At the time, this minimum was determined to be equivalent to, or better than, at least one accessible PC with a 486 CPU, 8 MBs of RAM and a 28.8 kbps modem with a GUI interface WWW browser such as Netscape. Partners already meeting the minimum standard were permitted to apply the funds towards the purchase of another minimum machine or to increase their existing capacity by adding modems or RAM to stand alone PCs, or adding PCs to an Internet connected LAN. The focus on PCs, as opposed to Apple or UNIX based systems, was determined by the preferences of the partners and not CWHPIN.

Partners accepting the funds to increase their technological capacity were asked make a commitment to contract with an Internet service provider so that the technology would be used for electronic connectivity. Some partners requested that CWHPIN locate an Internet Broker that could supply all partners with Internet services at a reduced rate, with common software and standardized service. No single Internet service provider covered all of central western Ontario, therefore, we asked several providers to bid on a contract that would involve them providing services to the whole region by sub-contracting services from other providers in those areas they did not currently serve. Only one organization appeared to be in a position to act as a broker. They also had the advantage of already serving a large portion of central western Ontario. As it turned out, they provided good service in areas where they served directly, but had difficulty sub-contracting for services when serving partners outside their area. Given the competitiveness and instability of the new industry of Internet service provision, CWHPIN recommends that contracts be taken for short terms and where minimal up front investment is required. This allows the partner to easily move if service deteriorates and reduces the risk of loss of investment if the company goes bankrupt, which did happen to one provider in our area. It was also recommended that each partner purchase their own domain name so they may change providers without having to redo letterhead or waste time rerouting e-mail.

CWHPIN only had start-up money to offer partners, therefore, we opted to provide a one time contribution to partners provided that they committed to absorbing the ongoing operational costs associated with maintaining a contract for Internet services. This approach was completely successful, with all partners receiving funds and securing contracts within the 6 months of the approval of the plan.
2.4 Internet training

Based on the survey of partners, it was determined that benefits would be derived from training staff in each partner agency to utilize the electronic communications network. A professional computer training company was selected to provide one full day of hands-on Internet training to members from each partner agency. The course was designed to provide a detailed overview of the services available on the Internet. These included an introduction to the Internet, connectivity issues, locating information on the World Wide Web using browsers such as Netscape, using e-mail including file attachments, listservs, newsgroups, bulletin boards, Internet relay Chat (IRC). Participants were expected to be able to rely upon their day of training and the training manual to provide basic support to other staff members. Both experienced and inexperienced users reported benefiting from the day of instruction. Training was not scheduled until the attendees had Internet connectivity. This requirement was imposed to ensure the trainee could apply the knowledge upon returning to their work site. This criteria acted as a further incentive for partners to establish Internet service contract.

2.5 World Wide Web page development training

Two months after the Internet training, a hands-on web page development training session was provided to at least one person from each partner. This goal of this training was to provide the partners with the capacity to create web pages that could be posted to a web site. The emphasis was on how to develop a quick loading page with useful content as opposed to a slow loading presentation focused page. The goals of this training were 1) to encourage all partners to start using the CWHPIN WWW site (http://cwhweb.mcmaster.ca) as another means of disseminating information; and 2) to enable them to independently maintain a web site of their own. The later goal provides the advantage of fostering independence by increasing capacity, which frees the CWHPIN webmaster from the task of maintaining all of the partner web sites, a task that could easily consume a full time equivalent. The web page development training was carried out in small groups by CWHPIN's Internet consultant, a computer science co-op student. The training continues to be supplemented by follow up support provided by our Internet consultant, who has set up a web page development discussion group in the Internet. In addition to partner representatives, CWHPIN's regional working groups, comprised of partner staff, also sent in members for web page training. This approach fits in with our policy that CWHPIN will administer the web server and create space for partners to disseminate information, but that partner staff are responsible for the updating and maintenance of each individual web site.

2.6 CWHPIN World Wide Web site (http://cwhweb.mcmaster.ca)

As part of the technology acquisition plan CWHPIN set up a WWW site on our Windows NT server using the Microsoft Internet Information Server. This package was selected because of its obvious compatibility with windows NT and the fact that it was free to licensees of Windows NT. All partner were allocated directories within which they could create as many sub-directories as required to host their web pages and other documents. Some partners already had web sites established, in which case a hot link was created to point visitors to the partners web site. Information considered relevant to more than one partner is stored in the CWHPIN section so it is easily located by users and replicate copies are avoided. This information is organized by category within the web site. All web site developers have been encouraged to keep web pages simple and uncluttered. Information stored on the CWHPIN web server includes; policy documents, reports, public use data sets, free software, links to other relevant sites, contact directories, and library service information.

The three main principles used to develop this web site have been: 1) that content and organization of information is the most important feature of a web site; 2) that partners maintain their own web sites on the server so the CWHPIN webmaster is responsible for server issues and occasional technical support; and 2) that only publicly accessible data can be placed on the web server due to our inability to maintain data security on an Internet accessible web server. The reason we set up an Internet server as opposed to an Intranet server is that wide dispersion of the partners would require the establishment of a WAN for which the costs would be prohibitive. We also wanted partners to be able to disseminate information to the public from their web site, a feature less easy to implement with an Intranet server.
2.7 Searchable database linked to the CWHPIN web site

In anticipation of the large volume of data that will be accessible through the CWHPIN web site a searchable database is being implemented. This searchable database is designed to allow partners to enter and access many types of data through the CWHPIN web site. This feature allows users to access a much larger amount of information in a variety of views, by simply querying the data base. It also makes the contents of the web site much easier to manage. Updating records such as a contacts address can be done in the main file and then subsequently viewed web pages pertaining to that individual will contain the updated address. Without this web-database feature the webmaster would be required to locate all occurrences of that individual and update their address.

2.8 Workshops/tools/CDs

Another connectivity strategy employed at CWHPIN is the hosting of workshops that illustrate tools and techniques for managing and processing health information. These workshops are useful ways of identifying the best tools and approaches to promote for partners. One such workshops was the State of the Environment Workshop (SOE) hosted by CWHPIN and Waterloo Region Community Health Department. A demonstration of the CWHPIN's pilot SOE web site was given and feedback obtained as to how this site could better serve the partners. As a result revisions were made and the partners now derive more benefit from their ability to access the CWHPIN SOE site using the electronic communications network.

3.0 Summary

Within a period of less than 10 months, CWHPIN identified our 15 partners needs for technology, developed a flexible and focused technology acquisition plan; allocated equipment to partners; provided Internet training and web page development training to all partners; all partners have an Internet connection with Netscape and a 28.8 kbps modem; developed a CWHPIN web site accessible to all partners through the Internet; developed a web-linked searchable database; and hosted workshops to further benefits to users of the CWHPIN electronic communications network. The success of this project was possible due to the commitment of all CWHPIN partners and staff towards a common goal and the continued support and vision of the Ontario Ministry of Health.

4.0 References


A Homepage on the Internet for The Vancouver Island Cancer Centre

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Keywords: Internet; Computer; Cancer Information; World Wide Web; Homepage

Abstract

The Vancouver Island Cancer Centre, British Columbia Cancer Agency has posted a Home Page on the World Wide Web (WWW). We believe that this home page is the first of its kind posted on the Internet for any cancer treatment organization in Canada. The VICC home page serves as an entity that can reach out to the local community, communities world-wide and establish a general awareness of the presence of the British Columbia Cancer Agency. Thus, the Agency's vision of reaching out to the community is no longer a vision. Cancer patients, physicians, health care professionals, and the general public around the world have the opportunity to learn about the Agency's goals and how we are trying to achieve those goals. In addition, the home page provides a host of cancer related information by linking the end-users computer to various cancer related WWW sites. In turn, these sites provide links to even more sites and so on.

While it is obvious that not every cancer patient has access to the Internet, it is possible that they can learn of the Agency through family and friends that do.

The VICC Home Page also provides an e-mail link to the centre. This allows anyone to e-mail comments, questions, and additional requests for information to the Agency.

1. Introduction

We believe the Vancouver Island Cancer Centre (VICC) of the British Columbia Cancer Agency (BCCA) has the first World Wide Web (WWW) home page posted on the Internet for any cancer related organization in Canada. The VICC home page is designed to link the Centre to the local and global communities and promote a general awareness of the presence of VICC and the BCCA. Cancer patients and their families, physicians, health care professionals, and the general public have an opportunity to learn about the Agency's goals and our efforts to achieve these goals. In addition, the home page provides a host of cancer related information by supplying hypertext links to various cancer related WWW sites. In turn, those sites provide links to even more sites and so on. The amount of information that is available on the Internet is extensive. Not every cancer patient has access to the Internet; thus, it is imperative that we seek partners to make this service as accessible as possible. Public libraries, educational institutions and Corporate sponsors may help bridge this gap.

2. Methodology

The World Wide Web, sometimes called WWW is built on a subset of computers on the Internet. The Web is made up of a series of connected documents. Connections are called Hypertext links or hyperlinks. These hyperlinks allow one to click with a mouse on a highlighted word or picture and jump to a related subject. The Web takes hypertext a step further by linking not only text, but also pictures, sound, and video. The term Web describes everything this hyper media system can capture. The term Web also describes how this collection of information fits together. There is no central hierarchy that organizes documents. To move data over the Internet, the Web uses a new protocol,
called HTTP (Hypertext Transport Protocol). To create the links between documents it introduces a new way to present data, called HTML (Hypertext Markup Language).

A home page on the Internet for the Vancouver Island Cancer Centre was created using hypertext markup language (HTML). HotDogTM (Sausage Software) was used as the authoring program for HTML. Several graphic files were created by scanning photographs and illustrations into GIF format. In addition, several documents existing in Microsoft Word 6.0 TM format were converted to hypertext, again using HotDogTM. The web page and associated files were tested with a web browser, Netscape NavigatorTM 2.0 (Netscape Communications), prior to downloading through a local Internet provider, IslandNet TM.

3. Results

The current link to the Universal Resource Locator (URL) is http://www.islandnet.com/~vicc. The Vancouver Island Cancer Centre Home Page provides links to the following information for cancer patients:
* Your First Visit Brochure
* A Map of the Centre
* Patient Services Booklet
* Coping and Caring Support Groups Brochure

There are no local documents describing clinical management policies and guidelines at present, though it is hoped to include these in the future. The VICC homepage provides links to other cancer related WWW sites for health professionals. These links include:
* American Cancer Society
* Cancer Net Web Server
* Fred Hutchinson Cancer Research Centre
* NCI CancerNet
* University of Pennsylvania's Oncolink

The Departments and Services of the Vancouver Island Cancer Centre are also provided from the Patient Services Section of the home page. The departments and services available are:
* Chemotherapy
* Clinical Trials
* Health Records
* Medical Staff
* Nursing
* Nutrition Services
* Patient and Family Counseling
* Patient Library & Resource Centre
* Pharmacy
* Radiation Therapy and Clinical Physics

In addition, the home page provides a telephone directory for VICC as well as mailing addresses for the BC Cancer Agency and the Canadian Cancer Society.

Finally, the VICC Home Page provides an e-mail link to the centre. This also allows the relevant VICC staff to reply to questions and comments by email, as well as telephone and postal service. The e-mail will be coordinated by a contact at the Centre. This contact is one of the authors, Marc Gaucher, Education /Quality Improvement Coordinator at the Vancouver Island Cancer Centre.
4. Discussion - Future Direction

The Internet or 'Information Superhighway' is one of the most exciting technological developments of the 1990's. There is now a wealth of information available by electronic means. The VICC Web page is designed to serve as an additional source of information, especially for patients and health care professionals. It also provides a means for two-way communication. In this way, we can develop the service to meet the changing needs of our customers, whether they are patients, families or health care professionals. Thus, the VICC homepage will continually evolve as our community reaches out to us. Many of our traditional forms of communication will be mirrored and may eventually be replaced using the Internet and other forms of electronic data. As an example, we are examining the feasibility of using our homepage as a conduit for referrals from Vancouver Island physicians, thus minimizing the use of fax or regular mail. The next step will be to establish links to other related organizations such as the Canadian Cancer Society and National Cancer Institute.

5. Outcome Analysis

We have included a form and counter that will enable us to track our Homepage users. In this way, users will be offered an opportunity to complete a brief electronic questionnaire that provides us with demographic information and comments regarding potential services we might add. This information will also enable us to make better decisions in terms of a target audience and our Homepage promotional efforts.

References


Videophones for Medical Consultations

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Keywords: Evaluation, implementation, user’s requirements, communication, qualitative methods

Abstract

Videotelephones are presently expected to diffuse rapidly in the market due to adequate networking techniques (ISDN), rapid development of signal processing tools and agreements on telecommunication standards. The main obstacles for successful implementation of videophones and their cost, so far very high, is expected to decline. The potential of applications in health care is therefore of great interest. Videophones can be applied to medical fields where the use of images is necessary. Picture communication through videophones is likely to change the communication patterns of a society in many ways.

All the issues that arise when introducing medical decision-aids could be included within the scope of videophones in health care sector. These include the evaluation of decision-aids themselves and evaluating their impacts on users, patients, work environment and health care systems.

In order to measure the effect of such a modern technology in health care settings it has to be evaluated in three different phases, namely
- pre-implementation study phase
- implementation phase
- post-implementation

This work gives a short overview of the videophone technology and possible applications in health care. The application to remote consultation between surgeon and pathologist is discussed in some detail, based on a qualitative analysis of this communication process. Qualitative methods used were - participant observation, videotaping and interviews. A number of benefits are pointed out. These should be achievable with regard to color and contour fidelity. Videotelephones should be designed so that they are user-friendly in terms of installation and use. Effectiveness should be further investigated in post-implementation assessments, also including possible alterations in work routines.

1.0 Introduction.

1.1 Videophone

The basic videotelephony service is characterized by the simultaneous transmission of moving color pictures, and the speech of the actors involved in the action. A picture contains a lot of information. Live pictures communication, i.e. videotelephony, at different geographical locations normally requires a channel capacity of at least 216 Mbit/s. The available channels for transportation have rather a limited capacity. With the advancement of new compression techniques, it is possible to use low bit rates (≤ 64 kbit/s) for video transmission with two-way communication. The implication could be a reduction in cost and creation of a large market.
Videophone in general consists of the following components: Camera, Codec, Microphone and Speaker, Key set, Monitor. Some medical applications might demand additional facilities. Examples are: Document cameras (with higher resolution), Cursor manipulation, Scanner equipments, especially for radiologic images in health care applications. General requirements on the camera, the terminal and other necessary peripherals are discussed in [1]. The camera is used to transfer a broadband video signal to a codec (coder-decoder), where it is digitalized and converted into a format suitable for transmission over a digital circuit at the required bit-rate. The conversion is known as coding or compression. There are several sophisticated video compression techniques available in the market. At the receiving end of the communication a video codec acts as a receiver and decodes the incoming bitstream by performing operations which are inverse to those done by the coder parts.

The price of videophones are relatively high for the time being. The expensive part of the equipment is the codec. ISDN (Integrated Services Digital Network) is the sign of an upgraded network and every subscriber should have access to two 64 kbit/s and one 16 kbit/s connection on a single physical telephone line - basically the kind of line already available in most homes and public places. With the ISDN technique it is possible to transfer moving pictures. It is a huge investment to upgrade the ordinary telephone network. Secondly, a terminal with a very high built-in computing power, which makes them very expensive, is needed to enable picture communication possible.

With increasing demand price will go down. It is expected if the video terminal follows the same trend as other customer premises equipment has done the prices as well as sales will show drastic changes in the coming years.

1.2 Main obstacles

The three main obstacles for successful implementation of videophones seems to be: - technical complexity and performance, - network costs and - user requirements. The work so far has mainly been concentrated on the first two factors, especially on the engineering side. In this report some of the issues on the uses of videophones in the health care sector and users requirements are discussed.

2.0 Applications of videotelephones

Picture communication is likely to change the communication patterns of a society in many ways. Videophones could be used for communication and it provides ample possibilities for people with disabilities. The following groups may be benefitted [2]: Mentally retarded people, Speech impaired people, Hearing impaired and deaf people, Facilities in rehabilitation and medical treatment, Home care, Visually impaired people.

Videophones can be applied to medical fields where the use of images is necessary. Examples are: Pathology (Tele-pathology), Endoscopy (Tele-endoscopy), Dermatology (Tele-dermatology), Radiology (Tele-radiology) and Distance education.

2.1 Applications studied in this paper

On the basis of remote consultation two alternative applications were studied:
1. Surgeon <-> Pathologist (Tele-pathology)
2. District nurse <-> Doctor (General Practitioner) (Tele-dermatology).

In pathology, surgically removed cell and tissue specimen are studied with the help of a microscope for diagnostic purposes (PAD, Patologisk Anatomisk Diagnos). Videophones could be used to enable pathologists at larger hospitals to provide pathological services to smaller hospitals. The smaller hospitals very often lack pathologists. The services could be both routine services as well as emergency services when a pathological intervention is necessary. Videophones could also be a medium of communication for collegual consultation between pathologists and other category of care providers at different sites.

In surgeon-pathologist application a need for still image communication with cursor manipulation was necessary to facilitate connection of i) a scanner for radiological images ii) a separate document camera.
The nurse-doctor application is rather straightforward face-to-face application. It may be necessary to connect to a separate camera to view affected parts of a patient (dermatology).

2.2 Objectives of the work

The purpose of the project was to evaluate the possibilities and consequences of videotelephony in the health care sector. We participated mainly in the evaluation work to study:
- how effective communication, irrespective of distances between a patient and a care provider, can provide better consultation and an appropriate care plan,
- how to provide necessary specialist function available in the routine day to day patient care and thereby increase the care provider's competence,
- how users would be benefited by videophones and
- the users' requirements.

2.3 Methods

To conduct the evaluation study of videotelephones implication in health care applications we argue for evaluation at three different phases, namely:

- pre-implementation study phase
- implementation process
- post-implementation phase

2.3.1 Types of evaluation

Types of evaluation to be considered for evaluating medical decision aids are [3-6]:
1. Technical validation: It mainly includes the technical feasibility of a decision aid in a particular environment.
2. Content validation: This involves showing the correctness, accuracy and usefulness of a decision aid in respective environment.
3. Local revalidation: This could also be called field testing or functioning in a new environment. This involves showing the correctness, accuracy and usefulness of a decision aid for foreign institutions. That is, does a video picture retain its meaning when it is shared by means of communication media. It should be done in a way similar to validation in the original setting.

The scope of this document is restricted to the pre-implementation phases only and would provide a baseline for both the implementation process study and the post-implementation study. This study was carried out at the University Hospital in Linköping, a teaching and referral hospital in Linköping, Sweden, and at the community hospital at Motala some 50 kilometers away.

In the study, the following three qualitative methods were used [7] They are:
1. participant observation,
2. video and
3. interviews.

2.4 Data collection and analysis

2.4.1 Field observations and interviews

Field observations and interviews were carried out at two different places, namely: 1) The Motala Hospital and 2) The University Hospital at Linköping.

The purpose of the observation and interviews has been to study the way and procedures adopted to communicate with the Department of Pathology and how this communication could be improved by the introduction of video phones.
2.4.2 Video recordings of pathology conferences

Video recordings of the pathology conferences at the Department of Pathology were carried out. The recordings were done at two conferences and they were being studied afterwards consulting with pathology expertise on our findings.

2.4.3 Analysis of the Video recordings

Pathology and surgeon consultations do not rest on face to face communication. In our studies we found that even telephone conversation among the pathologists and surgeons were not very common. The telephone was used only in cases where there was time constraints and some clarifications to the written documents were needed. In the study we further observed that these consultations, with the exception of the teaching conferences, was mainly paper based and was largely an exchange of papers (reports, case notes) and data (e.g., specimens, slides).

In teaching conferences the data elements in the slides become part of a particular argument. The slides are shown and discussed in serial, progressive order. They in short possess directionality and are used to motivate a particular interpretation, to make a particular diagnosis, to argue for or against a particular clinical action.

3.0 Results

The video-phones with its symmetrical bidirectional, real-time, audio-visual teleservice could help in the communication between the two or more sites. Primary benefits of a videophone system observed and indicated by pathologists and/or surgeons were:
- pedagogic value of discussing over pictures compared to the written report,
- the benefits are prominent when for instance the radicality of a cancer operation has to be discussed
- acute report during surgical operation,
- consultation with experts at distant places,
- quicker investigation of difficult cases when surgeons and pathologists have opportunities to discuss over pictures. This might mean 1) higher reliability, 2) time gain also meaning cost reductions.

Certain secondary effects might be apparent when the videophone system has been implemented.

4.0 Discussions

The report discussed in brief the technical aspects of videotelephone. Videotelephones should be designed so that they are user-friendly in terms of installation and use. In order to measure the effect of such a modern technology in health care settings it has to be evaluated in three different phases, namely
- pre-implementation study phase, - implementation phase and - post-implementation

This work is mainly concerned with the pre-implementation study phase. The methods involved and the results obtained show a positive inclination towards videotelephone application in distance collegial consultation in health care setting. In pathology consultation specially in teaching conferences slides are being used as an argumentative instrument [7]. Videotelephones could be useful to provide long distance microscopy to best support the kinds of practical reasoning and labor that make up a pathology consultation. The communicative potential of videotelephones over distance could bring positive changes in health improvement.

Acknowledgements: This work was supported by the Swedish Telecom. Field research was carried out in collaboration with Drs. James Nyce and Toomas Timpka, Department of Computer and Information Science, Linköping University. Dr. Bernt Boeryd of Linköping University Hospital provided help in data collection and analysis. Besides a number of physicians, surgeons, nurses and other support staff were interviewed. We would like to thank them all for their help.
5.0 References


Community Health Information Systems - 2

Chair: Marilynne Hebert
Minimum Data Set for the Community Rehabilitation Program in Alberta

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Keywords: community health, rehabilitation, minimum data set.

Abstract:

Alberta Health and the Regional Health Authorities (RHAs) began implementation of the Community Rehabilitation Program (CRP) on July 1, 1995. This program is intended to meet some of the rehabilitation needs of Albertans by providing audiology, occupational therapy, physical therapy, respiratory therapy and speech-language pathology services in a community based setting. The mandate for CRP is to deliver goal directed, client-centered, needs based and outcome driven rehabilitation services to Albertans.

During implementation of the program, Alberta Health and the RHAs recognized the importance of collecting data in a standardized manner in order to support the program. This led to the initiation of the CRP Minimum Data Set project. The project's primary objective was to define a standardized minimum set of data to be collected and used by clinicians who provide rehabilitation services through the CRP and to be used by Alberta Health to support the Minister.

The presentation to ITCH '96 will cover the following topics related to this project:
- Overview of the consultative approach taken to define the Minimum Data Set;
- Definition of a Minimum Data Set;
- Overview of the deliverables from this project; and
- Update on the current status of the CRP Minimum Data Set.

1.0 Introduction

Alberta Health and the Regional Health Authorities (RHAs) began implementation of the Community Rehabilitation Program (CRP) July 1, 1995. This program is intended to meet some of the rehabilitation needs of Albertans by providing audiology, occupational therapy, physical therapy, respiratory therapy and speech-language pathology services in a community based rehabilitation program that is goal directed, client-centred, needs based and outcome driven. The vision of CRP is integration within Community Care through the Regional Health Authorities, and coordination and integration with other rehabilitation services in acute care, long term care, tertiary care, other Community Care programs and private practices in the Regions.

In order to develop information systems to manage health information more effectively, data must be collected in a standard manner. One of the next critical steps identified for the implementation of CRP in the health regions was to define a Minimum Data Set. This Minimum Data Set would be used by the providers of rehabilitation services under the jurisdiction of the Regional Health Authorities as well as by Alberta Health to support the Minister.

The CRP Minimum Data Set project was initiated to consult with representative working groups and discipline specific focus groups to define a Minimum Data Set for the Community Rehabilitation Program. The project was requested by the CRP Implementation Group and coordinated and funded by Alberta Health. The CRP Implementation Group, which consists of CRP managers from the seventeen Regional Health Authorities, meets regularly to address CRP implementation issues.
The objectives of the project were to:

- define the standardized Minimum Data Set required by clinicians who provide rehabilitation services under the jurisdiction of the Regional Health Authorities for the five disciplines of:
  - audiology,
  - occupational therapy,
  - physical therapy,
  - respiratory therapy and
  - speech-language pathology;

- identify the Minimum Data Set that is needed by Alberta Health to support the Minister;

- make recommendations for the next steps required by Alberta Health to use the Minimum Data Set.

2.0 Overall Project Approach

The project used a consultative approach to define the CRP Minimum Data Set. Facilitated work sessions were held with:

- an Internal Working Group whose participants represented several branches within Alberta Health;
- an External Working Group whose participants included CRP managers and others from the Regional Health Authorities; and
- five discipline specific focus groups with clinicians from each of the CRP rehabilitation disciplines: audiology, occupational therapy, physical therapy, respiratory therapy and speech-language pathology.

2.1 Initial Work Sessions with the Internal and External Working Groups

An initial facilitated work session was held with each of the Internal and External Working Groups to start the process of defining the CRP Minimum Data Set. The objectives of these two work sessions were to:

- introduce the project, its scope and objectives;
- identify the key benefits for defining a CRP Minimum Data Set;
- define the criteria that should be used to include or exclude a data element from the data set; and
- identify an initial set of data elements that should be included in the CRP Minimum Data Set.

2.2 Focus Group Work Sessions

Following these initial sessions, a series of five facilitated focus group work sessions were held with representatives from each of the CRP disciplines. A member of the External Working Group participated in each focus group session to provide continuity between the groups. The objectives of these sessions were to:

- refine the list of key benefits identified at earlier sessions;
- refine the list of inclusion/exclusion criteria identified at earlier sessions;
- identify and define additional data elements where required; and
- build on the data elements that had already been identified by refining the definitions and adding values where applicable.

A building process was used in each of the work sessions in order to capitalize on the work that was completed by previous groups and target areas where refinements were required. Mid-way through the focus group work sessions a second half day work session was held with each of the Internal and External Working Groups to review issues that were raised in the focus group sessions and to re-assess, using the inclusion/exclusion criteria, the data elements that were identified to-date.
2.3 Final Model Review Session

A final one and a half day work session was held with all participants from the Internal and External Working Groups, and the discipline specific focus groups. The objectives of the first half day session were to:

- present the work completed to-date on the CRP Minimum Data Set; and
- present the topics to be addressed by multi-disciplinary teams the following day.

During the second one day session the participants were divided into seven multi-disciplinary teams and assigned specific data elements. For each data element the team was asked to provide consensus based input on the following:

- rationale for capturing and storing the data element;
- rules for capturing the data element; and
- format specifications for the data element.

In addition to this the team was asked to validate the data element's definition and values to confirm that they were correct, concise and complete. Worksheets with a starting set of rationale, business rules and format specifications for all the data elements were provided to the participants.

The majority of each team's results were briefly presented at the end of the day for feedback from the entire group. Copies of the results were sent out to all participants the next day and feedback was requested by the following week. The results of this work session and the feedback received were used as input to finalize the CRP Minimum Data Set.

3.0 Definition of a Minimum Data Set

The "minimum data set" definition used by this project was the least number of items of information which will provide most of the data required by the majority of users. The users of the CRP Minimum Data Set were described in terms of three levels in relation to the health care system in Alberta:

- the strategic level which represents the responsibilities of Alberta Health;
- the tactical level which represents the responsibilities of the Regional Health Authorities; and
- the operational level which represents the responsibilities of clinical providers.

The CRP Minimum Data Set represents a core set of data elements that would be used by multiple users across these three levels. From this core set of data elements additional data may be derived. For example, age is derivable if both date of birth and the current date are captured as part of the core. Although the core set of data elements is intended to serve multiple purposes, supplementary data outside of the CRP Minimum Data Set is expected to be collected to meet the needs of specific sets of stakeholders.
CRP Minimum Data Set

As described in the Overall Project Approach section, the CRP Minimum Data Set data elements were idMinimum Data Set for the Community Rehabilitation Program in Alberta.

For each data element in the CRP Minimum Data Set the following items were specified:

- Definition;
  
  An explanation to promote clarity and understanding of the data element.

- Valid values (where applicable);
  
  Where there is an existing classification system, coding structure or set of values that can be selected from when recording the data element, these values were identified, listed and where required each value defined.

- Rationale for capturing and storing the data element;
  
  The rationale for collecting each data element has been defined in terms of who will use it, the form it will be used in and how it will be used. The form of use, identifiable or anonymous, only applies for those data elements that can be used to identify individuals. The anonymous form implies that data will be encrypted when viewed or aggregated so that the individual cannot be identified.

- Business rules for capturing the data element.
- Rules related to how and when the data element should be captured to ensure that the data will be useful.
The data elements included in the CRP Minimum Data Set are as follows.

Service Event Base Data Elements:

- Service
- Service Event Date
- Delivery Organization
- Delivery Site
- Delivery Site Type

Service Event Recipient Data Elements:

- Personal Health Number
- Amount of Time
- Number in Group

Service Event Provider Data Elements:

- Personal Health Number
- Provider Type
- Provider Discipline
- Amount of Time

Base Stakeholder Data Elements:

- Stakeholder Type (i.e. person or organization)
- Date of Birth
- Gender
- Postal Code

Service Specific Data Elements:

- Diagnosis
- Referral Source
- Referred-To Agency
- Determination of Needs Score
- Goal Achievement

5.0 Recommendations for Implementation

Two final work sessions with the Internal and External Working Groups were held to develop recommendations for implementation of the CRP Minimum Data Set. The recommendations were defined to address issues, concerns and needs raised by the Working Group participants as well as those documented during the focus group work sessions.

The recommendations developed address the following five areas.

5.1 Verification and Evolution of the CRP Minimum Data Set

The recommendations in this area focus on steps required to verify that the data element definitions and values are sufficiently concise and complete to ensure that the data collection and use will be consistent across the province. Recommendations were also made on the process required to ensure that the CRP Minimum Data Set evolves along with the business of delivering health services to Albertans.
5.2 Development of Policy and Guidelines

To ensure efficient and effective collection and use of the CRP Minimum Data Set across the province, recommendations were made for the development of specific policies and guidelines. In particular, policies and guidelines relating to the protection of privacy for individuals and confidentiality of both provider and recipient must be developed.

5.3 Communication Strategy

To promote comprehension and acceptance of the CRP Minimum Data Set among both providers of CRP services and recipients of those services, recommendations relating to a communication strategy were developed.

5.4 Training Strategy

In addition to a communication strategy, recommendations were made to address both the initial and ongoing training that will be required by those individuals who will be collecting or using the CRP Minimum Data Set.

5.5 Development of Systems for the Data Collection and Use

The final set of recommendations recognize the need for reliable information systems to support the collection and use of the CRP Minimum Data Set. These information systems must enhance and not disrupt the natural flow of delivering health services.

6.0 Conclusion

To maintain the momentum started by this project, it was recommended that a pilot be conducted before full implementation of the CRP Minimum Data Set across all Regional Health Authorities and at Alberta Health. The intention of the pilot was to:

- verify the data element definitions and values;
- test the business and technical infrastructure for effective and efficient collection and use of the data at the clinician, Regional Health Authority and Alberta Health levels;
- assess the feasibility of collecting those data elements that have been marked as placeholders due to implementation issues; and
- evaluate the use of the data elements and the information generated.

The planning phase of this pilot would define the detailed objectives of the pilot, select the appropriate pilot sites and address integration with other related initiatives.
7.0 References:


The Development of a Conceptual Design for a System to Support the Information Needs of the Long Term Care Program

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Abstract

The Long Term Care Program is one of six programs comprising the Care Programs Division within Capital Regional District Health. The manager and case workers of the Program, seeking to increase its effectiveness through more efficient information management, want a computerized system which will provide client information to support day-to-day operations, as well as statistical information to support administrative decision making and planning. In collaboration with the School of Health Information Science, the Program began a project in September 1995 to develop a conceptual design for such a system.

Based on an object-oriented information engineering approach to system design, the project was divided into three phases: planning, analysis, and design. The main objective of the first phase was to develop a description of what case managers do and their role in the business of the Long Term Care Program. This high level view of case management was graphically depicted using a modeling tool called a Function Hierarchy. During the second phase, functions were analyzed in detail using another modeling tool, the Event Response Diagram, in which data elements necessary to support each function were listed. Finally, the data elements identified during the analysis phase were incorporated into a conceptual design for the information system using a third modeling tool, the Entity Relationship Diagram.

This systematic approach to modeling the reality that the information system is intended to support ensures that all necessary data elements are included and the decision support needs of all users are addressed. It is anticipated the information system based on this design, once completed, will not only support the information needs of the Long Term Care Program but will also enhance strategic information management throughout the Care Programs Division.

1.0 Introduction

The Capital Regional District (CRD), encompassing approximately 2,400 square kilometres on southern Vancouver Island and the Gulf Islands, is one of 30 incorporated regional districts throughout the province of British Columbia. Serving about 300,000 people, the CRD administers more than 70 services, including health services. Capital Regional District Health (CRD Health) employs over 360 people who provide Health Promotion Programs, Epidemiology and Disease Control, Health Protection and Environment Programs, Health and Hospital Planning, and Care Programs.
The Care Programs Division of CRD Health provides a range of community based health services to support the ill, the disabled, and the elderly, helping them retain their independence within the community as long as possible and, when necessary, assisting them with facility placement. The Care Programs Division offers its services through six programs: the Long Term Care (LTC) Program, Home Nursing Care, Community Rehabilitation, the Quick Response Team, Central Intake, and Hospital Liaison. Information used by these programs is now principally maintained in program-specific files. While some of the files are maintained in electronic form, most are paper-based and there is little integration of files among or even within programs. The project described herein is the first step in the development of an information system for Care Programs which will provide current, relevant, accurate, and integrated information, when and where it is needed. The vision is for a computerized information system which will contain client demographic data, as well as relevant clinical process and outcome data [1].

Development of such a system is consistent with a recent directive from the British Columbia Ministry of Health and Ministry Responsible for Seniors. The Ministry, through its Health Information Management Project (HIMP), is encouraging health care providers throughout the province to strive for "effective and efficient management of information" [2]. In September 1995, the Long Term Care (LTC) Program, in collaboration with the School of Health Information Science, began work toward achieving this goal. The following describes the initial steps in the project which is still in progress. It also relates some of the practical problems encountered and how they were resolved.

2.0 Objective

The purpose of the project was to develop a conceptual design for an information system that would be flexible enough to satisfy three functions. It must be able to:
1) support the day-to-day case management operations of the Long Term Care Program;
2) provide decision support to Long Term Care Program managers; and
3) provide planning information to Care Programs Division administrators.

Further, the system must provide the facility to assess the success of these functions based on client outcomes, an objective that is consistent with the emerging concept of evidence-based health care.

3.0 Context of the Project

3.1 Definition of Case Management

The primary function of the Long Term Care Program is case management. "Case management is a standard process to identify client needs and allocate Ministry of Health resources to service those needs" [3]. The process starts with client intake and ends with client discharge or death. Throughout the process the case manager assumes many roles, such as counselor, educator, assessor, and service coordinator.

3.2 Present Structure of Case Management

Today Case Management within CRD Health is essentially a paper-based system. Although case managers occasionally use computers to check client numbers, they rely on cardex files for client demographic information and on clients' paper charts for case information. The only summary information available is a monthly report from the Ministry of Health Continuing Care Division listing cases due for review.

3.3 Practitioners of Case Management

Individuals employed as case managers by CRD Health are either Registered Nurses (BSN prepared) or Social workers. Regardless of their discipline, their basic duties are the same.

4.0 Methodology

An object-oriented information engineering approach to systems development was employed. This top-down approach refers to an integrated set of methodologies for creating and operating information systems that is based on the use of "objects," that encapsulate both metadata and the processes that use those data. While several versions of
the information engineering concept exist, this project was based on the work of James Martin [4], Stephen Montgomery [3], and R. Barker et al [6]. Martin proposed a four phase project life cycle: planning, analysis, design, and system construction [4].

4.1 Planning

Martin, Montgomery, and Barker recommend development of an information strategy plan as the first step in the information engineering process. The information strategy plan is concerned with the goals and targets of the business and with how technology can be used to create new opportunities or advantages. The plan should produce a high-level model of the business [4,5,6].

The modeling tool used was the Function Hierarchy. Function Hierarchies, graphical depictions of business activities at their highest level, provide a relatively stable foundation for system development. They include definitions of what activities must be performed in order to manage an organization, not how these activities are performed. So defined, these function descriptions tend to change little over time [5]. A preliminary version of the model, based on information gleaned from brainstorming sessions and documentation review, was developed using Oracle CASE software and presented to the project team. The model was critiqued by the team and revised accordingly. The revised model served to guide team discussions through subsequent phases of the project and, as a result of these discussions, it was frequently revisited and further refined.

Although ten main functions had been identified, only one function at a time was developed to prevent the team from being overwhelmed. Dividing the project into sub-projects helped to make it more workable. For example, the boundary for the first sub-project was set to include only two functions: "New Assessment" (Figure 1) and "Develop Care Plans".

![Partial Function hierarchy for home care](image)

Figure 1 - Partial Function hierarchy for home care

4.1.1 Challenges of the Planning Phase

Development of a Function Hierarchy appears relatively straightforward. In practice, it was quite difficult for the team to think in terms of the model and its semantic rules. The tendency was to think "upside down". For example, because telephoning takes so much of the case managers' time, it was thought of as a primary function instead of a supportive one. Asking the question, "What do you need to do to complete Function X?" helped to place each function at the appropriate level. Any activity that had to be done as part of "Function X" was automatically placed below that function. Consequently, "do telephone consultation/interview" became a sub-function of many higher level functions.

The same question also helped the team to identify individual functions. Case managers frequently perform more than one function at a time. Consequently, they thought of these groups of activities as only one function. Whenever the process began to flounder because of this tendency, the "What do you need to do to complete Function X?"
question was applied to the functional group. Analyzing the answer helped to separate activity clusters into the primary functions of case management.

4.2 Analysis

The objective of the analysis stage is to describe exactly what actions are necessary to make the business work [6]. This is achieved by expanding the Function Hierarchy into sufficient detail to ensure an accurate and complete foundation for design. The Function Hierarchy is expanded into the temporal domain using another modeling tool, the Event Response Diagram. The Event Response model clearly describes the step-by-step actions that occur when an external stimulus, or event, activates the system. Detailing a system's response to the event is necessary in order to capture the system's overall data and information management requirements [5].

Event Response modeling was done by having case managers describe their activities in detail. The continuity of the diagrams was verified by ensuring they coincided with a path through the Function Hierarchy moving from the highest to the lowest level. Once the Event Response diagrams were drawn, the data elements needed to support each event were listed. The data elements were determined by examining any forms used during a particular event or by having case managers relate what data they needed to perform a particular activity. While the strategy, at first, was to consider every event and response as critical to case management, some were found to have little impact on case management and were subsequently eliminated from the diagrams.

![Event response diagram](image)

Figure 2 - Event response diagram for "initiate care planning by central intake form" function

As the analysis progressed the Function Hierarchy was continually revised to reconcile any inconsistencies between it and the Event Response models. This also provided an opportunity for analysts and users to develop more precise descriptions of each function. Descriptions were developed by drawing on the expertise of the case managers and by surveying existing documentation such as the Case Manager Guidebook, a Ministry of Health publication [3] that describes the policies and procedures case managers must follow.

4.2.1 Challenges of the Analysis Phase

Maintaining interest in the project was the key problem during the analysis phase. Explanations of what was being done and why it was being done were given to LTC Program staff. Nevertheless, case managers experienced considerable frustration at having to take time out of their busy schedules to discuss the level of detail necessary to produce accurate Event Response diagrams. Further, the more detailed the discussions became, the more easily they strayed off topic. Strong moderation was needed to maintain the project's momentum. Perhaps if more time had been taken during the planning stage to communicate what the systems development process entails, less frustration would have developed at this stage.
4.3 Design

The final objective of this project was to organize the required data elements into a conceptual design for a database. A conceptual design, also called a logical or preliminary design, is a working concept of an information system before it is implemented. The concept shows prospective users what the proposed system will be like and what it will do. It uses terms that are familiar, and therefore logical, to the users so they can understand the model and resolve any potential problems prior to the implementation of the system.

The modeling tool used to produce the design was the Entity-Relationship Diagram (ERD). An ERD includes abstract representations of real-world entities (e.g. organizations, clients, case managers, assessments, interviews) and the relationships between entities (e.g. a client HAS assessments, assessments ARE PERFORMED by a case manager). It is a blueprint for the design of a database which may be implemented in paper form or on a computer [1]. The design for this project was based on:

1) the data elements and their relationships identified during the project; and
2) the guidelines enumerated by the HIMP and published as the B.C. Health System Minimum Shared Data Set [7].

A preliminary version of the design was produced, critiqued by the project team, and revised accordingly. The entities were further developed into objects by the inclusion of some processing logic (e.g. calculate age, create schedule). The processing logic was determined by what information was most commonly used by case managers and administrators, and also by what information they suggested would be helpful to them.

The final step in preparing the design was to normalize it. Normalization is a process applied to database data sets to minimize the opportunity for errors, make data management easier, and optimize the flexibility of the data set (maximize the number of ways the data can be queried). It involves minimizing duplication of data among the entities or objects and isolating dependencies between data elements. The design was taken to third normal form [6] but was denormalized in some areas for space and performance considerations. The current version of the design is shown in Figure 3.

4.3.1 Challenge of the Design Phase

Since it is not feasible to include every detail in the design, decisions had to be made to as to which data elements were trivial and could be safely excluded from the ERD. The case managers and administrators assumed responsibility for these decisions.
5.0 Discussion

This project underscored three important points. First, development of a system for the Long Term Care Program will take a considerable amount of time and effort, more than was originally expected. Second, the process is not possible without serious commitment from both case managers and administrators. Finally, a strategic plan for the entire Care Programs Division is required if the work done in each of the program areas is to be integrated into one enterprise-wide system.

While this project made a start at developing a system to support the Long Term Care Program's information needs, more analysis remains to be done before the design for the system is complete and programming of the system can begin. Remaining tasks include:

1) further normalization of the ERD;
2) incorporation of additional processing logic into the objects;
3) completion of the data inventory for pick lists;
4) development of a Data Dictionary for all data elements listed in the conceptual design;
5) development of the remaining sections of the Function Hierarchy; and
6) integration of future results into the current conceptual design.

The complete system will allow managers and administrators to measure the resources expended in case management. For example, the time taken by a case manager to perform a particular function could be measured over a specified period. These times could be averaged over all case managers and the results used as a standard resource utilization indicator for that function. The finished system will not only provide workload statistics, it will also enable Long Term Care Program personnel to link the information to a particular client or case manager and will provide the framework for correlating case managers' activities with client outcomes.
6.0 Conclusion

The increasing emphasis on client outcomes is creating a need for more information about how the actions of health care providers influence the health status of their clients. To this end, the Long Term Care Program initiated a project to identify the functions of its case managers and to determine the data elements needed to support those functions. The project employed an object-oriented information engineering approach to systems development and resulted in a conceptual design for a segment of a system to support the information needs of case managers and Long Term Care Program administrators. The project is still in progress. The work done to date should provide a sound foundation for future efforts. By building on what was done, the Long Term Care Program and its clients will, in time, realize the benefits of effective and efficient information management.

References


A Community Health Information System for the Emergency Department

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Abstract

Health care providers in the Emergency Department (ED) rarely have knowledge of their patients' past histories. Knowledge of a patient's medical history, including current medications, known problems, and past surgeries, can be invaluable in providing the best, most timely, and most cost effective care to a particular patient. However, this information is not typically available. Patients and their family members are often not reliable sources of information. Patients may forget the names of medications they are taking, or be upset causing them to forget or leave out details. Some patients may even purposefully withhold important information. Access to paper-based medical records is difficult and time consuming, at best. If patients are not from the local area, access to medical records is likely to be impossible.

The emergence of Community Health Information Networks (CHINs) enables the development of information systems which can provide critical information to Emergency Departments. An Essential Emergency Data Set (EEDS) has been identified that will provide the information that is important to ED clinicians when treating patients. This data set has been designed to supply a snapshot of the patient's medical history, including: allergies, current medications, problems, surgeries, baseline EKG's and other relevant data.

Using the information contained in many existing CHIN repositories, we are designing and building an information system to provide EEDS data to Emergency Departments today. In this paper we describe our design of such an information system, the advantages of using that system, and problems or obstacles to development that must be overcome.

1.0 The Problem

It is often difficult to get reliable medical history information for the patients who are seen in the Emergency Department (ED), and complete medical records are almost never available. The patients themselves are often unreliable sources of information. Getting copies of medical records is often very difficult, if not impossible. If the patient is from somewhere other than the immediate local area or receives care from local hospitals other than the current hospital at which the patient presents, clinicians may not even be aware that records exist. [1]
A common motto in Emergency Departments is, "Listen to the patient, but never trust anything a patient tells you." Oftentimes, patients arriving in the ED are scared, confused, or not thinking clearly for a variety of reasons, as are family members who may accompany the patient. In these cases, it is often difficult for patients and their families to remember current medications, past problems or conditions, and allergies. In other cases, the patient may purposefully mislead the physicians and nurses caring for them (e.g., drug seekers or those trying to cover patterns of abuse).

Obtaining medical records for ED patients is hit and miss, at best. If the patient has been treated at the hospital before, some limited medical records may be available -- provided the medical records department is open and provided that the patient's records have been appropriately filed and are not in another department of the hospital or on someone's desk. Sometimes, if the patient knows the name and phone number of his or her primary physician or knows where they have been previously treated, it may be possible to get copies of records faxed to the ED. If the patient is not from the local area, it may be impossible to obtain past records.

Lack of full knowledge of a patient's history makes it difficult for a physician to provide the best, most timely, and most cost-effective care. Sometimes patients cannot accurately recall or are unaware of conditions they have. Extra tests may be ordered and care may be delayed until test results are received, to confirm information provided by the patient or to confirm the physician's suspicions of a particular condition. In many cases, had a patient's records been available, the information provided in the record may have made such testing unnecessary. Thus, the number of tests the physician ordered may have been significantly reduced, saving time, reducing costs, and causing the patient less discomfort.

Patients often cannot list the medications they are taking, and may not know their allergies. Patients could potentially be harmed if they are given incompatible medications, or if they are given a medication to which they are allergic.

The development of a standard set of data elements essential to facilitate the most effective emergency care, along with the establishment of community health information systems that can become sources for individual, patient-specific information, can provide life saving medical history data for ED patients. [2]

2.0 The Essential Emergency Data Set

The Essential Emergency Data Set (EEDS) is an evolving national standard for displaying a high level view of a patient's past medical history. The data element categories include demographic and identification information, problem list, medications, allergies, dates and places of previous health care encounters, and an image of a recent EKG. The data set is purposefully structured to be efficient and compact, rather than representing a comprehensive electronic medical record.

Previous studies of the emergency care process have shown EEDS information to be partially or completely unavailable in a large number of emergency cases. When the data can be obtained, it often takes excessive time and effort, and not uncommonly yields inaccurate information. Availability of EEDS data through a national distribution network will provide caregivers with rapid access to reliable information. This information will lead to more accurate patient management decisions, saving time and money, and improving quality of care. [3]

Community health information systems, operating in Community Health Information Networks (CHINs), can store vital information about patients' medical histories (including EEDS), making this information available to hospital EDs in the community.

CHINs can be established as repositories for patient-specific information, providing local EDs access to patients' medical histories. A patient's medical history, stored at a CHIN, may contain EEDS information, as well as more detailed data about recent visits to other health care providers in the local area. By networking CHINs on a national level, patient medical data can potentially be accessed in any emergency department or health care facility across the country, or even across the world.
3.0 EEDS Implementation

For the past 18 months we have been engaged in an effort to define an infrastructure with the features necessary to bring the EEDS concept to fruition. These features include the capabilities to query, locate, search, retrieve, and store EEDS information. To understand the requirements to provide these capabilities and the ways in which they interact, consider the following scenarios illustrating how this infrastructure will be used.

3.1. Scenario 1

A 65 year old woman from Los Angeles is vacationing in Milwaukee with a senior citizens group. After having a large evening meal with her friends, the woman begins to develop chest pain. The pain is severe enough that the woman's friends take her to the local Emergency Department. The patient is a poor historian; she cannot recall the name of the primary care physician newly assigned by her HMO, and cannot name her medicines, except to state that she takes, "a stomach pill." She is allergic to, "an antibiotic," which caused throat swelling and a rash. She has had previous episodes of, "heartburn, up in my chest," and states that this pain had been so severe that she had, "that heart catheter thing," approximately six months ago. She is not sure of the results of this test.

The woman is immediately taken to the treatment area. She is placed on a cardiac monitor and given oxygen by nasal canula as the initial history and demographic information are obtained. Using the initially collected data, a query is constructed and sent to the Los Angeles regional EEDS repository where the patient's EEDS record is located. The patient's EEDS record is subsequently returned to the ED in Milwaukee. The EEDS record confirms a long history of complaints of chest pain, typically described by the patient as "heartburn." Her EKG, including one performed within the month, demonstrates nonspecific T wave changes. As a result of her persistent chest pain and borderline EKG, a cardiac catheterization had been performed six months ago and was noted to be completely normal. Endoscopy later showed a hiatal hernia with reflux, which was felt to be the cause of the patient's symptoms. She was started on cimetidine, with improvement of her symptoms. An allergy to sulfa is also noted.

Following a careful history and physical examination, review of the patient's EEDS record including comparison with the baseline EKG, appropriate lab tests, and a brief period of observation, the emergency physician concludes that the patient's symptoms do not represent myocardial ischemia but are instead due to aggravation of her previously documented hiatal hernia and reflux as a result of dietary indiscretion. No acute EKG changes are noted. She is given an antacid with good relief of her symptoms and is discharged. As a result, a potentially lengthy, disruptive, and expensive admission is avoided. The patient's EEDS record is updated and transmitted to the Los Angeles regional repository to reflect this ED visit.

![Figure 1. Interaction between Milwaukee Emergency Department and Los Angeles EED Repository](image-url)
3.2 Scenario 2

A 40 year old woman presents to the emergency department complaining of one day of frequent urination and burning with urination. She has not had a fever or other serious symptoms. Her history, physical examination, and urinalysis are all consistent with cystitis (bladder infection). Her pregnancy test is negative. The patient initially denied any drug allergies. The Emergency physician planned to prescribe trimethoprim/sulfamethoxazole, a sulfa antibiotic considered first line therapy for this type of infection. The patient EEDS, however, indicates that she had a previous rather serious allergic reaction to a sulfa drug. An alternative antibiotic is prescribed, and a serious allergic reaction is averted.

3.3 Scenario 3

A 6 year old child is brought to the emergency department by her parents. They states that the child tripped and fell down several steps. Review of the patient's EEDS reveals multiple visits to different emergency departments for a variety of traumatic conditions, including contusions, abrasions and a broken arm. Based on this pattern of injuries, the emergency physician suspects child abuse. Appropriate legal and social service intervention is arranged.

3.4 EEDS Infrastructure

For an EEDS query to travel from Milwaukee to Los Angeles as presented in the first scenario above, many components of the infrastructure must interact. First, there must be a standard definition of the data elements defining EEDS so that compatible repositories can be established. Each repository must have a means to decompose a query into the elements used to search the records of the repository so that the record(s) matching the query can be located. A query protocol language must be developed which allows queries to be composed, communicated, and decomposed. Mechanisms for locating records within a region, throughout a nation, or even throughout the world, must be in place and be able to interoperate. There must be security mechanisms and business rules to protect patient confidentiality, to maintain integrity of the data, and to ensure access to the data is not misused.

In the quest of developing the EEDS infrastructure we (as part of the National Information Infrastructure Health Information Network Consortium) have:

- defined the Essential Emergency Data Set,
- specified the functionality of a regional EEDS repositories,
- defined the business rules necessary for querying and updating EEDS information,
- specified a message protocol for querying, accessing, and updating EEDS information,
- defined mechanisms for intelligently locating EEDS records, and
- specified EEDS security mechanisms. [4,5]

EEDS, as it is presently defined, is composed of nine functional areas including demographics, contact information, allergies, medications, previous encounters, problem list, and EKG. The data set is comprised of elements which have been specified in conjunction with organizations establishing related data sets, including the American College of Emergency Physicians (ACEP), the American Society for Testing and Materials (ASTM) and the Centers for Disease Control and Prevention (CDCP). From this specification, logical and physical models were developed to provide the structure upon which the database schema for a pilot EEDS repository has been implemented.

The EEDS business rules have been specified defining:

- who has access,
- how access must be obtained,
- who is responsible for tracking security anomalies,
- allotted time frames between when records are accessed and when they are updated,
- how the repositories are to be populated, and
- how records are to be located on a wide area basis.
A communication protocol for querying and updating EEDS repositories has been specified. Similar to the Health Level 7 (HL7) protocol, this EEDS protocol is a byte-stream message language which defines the necessary information for performing the various transactions necessary to support EEDS.

We are currently conducting an EEDS pilot test program in metropolitan Milwaukee, Wisconsin, in the United States. Four hospitals are participating, and a large number of primary care physicians are accessing and updating EEDS information in a regional repository. The Wisconsin Health Information Network (WHIN) is providing an interface for primary care physicians to access EEDS. ISX Corporation and Preferred Medical Informatics have developed an interface for use in participating emergency departments as part of their patient tracking system, Emergency Medicine Log (EM Log™), to allow ED staff to access EEDS. The purpose of the pilot is to test the assumptions and mechanisms which have been designed for EEDS and to fine tune their function and performance for wide area use in 1997.

4.0 Conclusion

Medical records are often incomplete, inaccurate, or simply not available at the time of care in the Emergency Department. This can interfere with the quality, timeliness, and cost-effectiveness of emergency care.

In conclusion, we have participated in a unique program to provide an infrastructure that will improve the health care system through advanced nationwide computer networks sharing patient data through secure channels. Activities have included the definition of the Essential Emergency Data Set, establishment of a network of community health information systems to distribute and update EEDS, and initial testing of those systems.

We believe that the pilot program will provide an opportunity to test the EEDS concept, identify technical and business process problems, and develop solutions to these problems. Current plans call for expansion of this program to a number of sites throughout the country over the next 18 months, ultimately leading to a nationwide EEDS implementation in the future.
5.0 References


Considerations in the Implementation of a Child Health Record Information System

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Abstract

The implementation of a computerized child health record within Calgary Health Services began with the conversion and transfer of more than 125,000 existing records to a single copy of the Community Health Immunization Information System (CHIIS) developed by Alberta Health. Data entry for new and preschool child health records including demographic, vaccination, postpartum service and tracking information for children born or moving into the boundaries of the Calgary Regional Health Authority proceeded. By the end of 1996 there will be greater than 280,000 computerized child health records on nine separate CHIIS data bases.

From the 1994 initiation, there have been many and significant technical and procedural issues related to CHIIS implementation. This paper details the events, interventions and results of actions related to staff training and performance, policy and procedure development, record management and data entry, and technical performance issues. Benefits and tangible gains will be highlighted.

Introduction

The provincially developed Community Health Immunization Information System (CHIIS) was implemented within Calgary Health Services July 1994. The system was established on a wide area network linking 13 community based offices to a single shared data base. There are now nine distinct CHIIS data bases in use at over 50 computer terminals within 16 offices. The following provides a summary of some of the successes and challenges encountered with CHIIS implementation that may be of use to others considering similar applications.

CHIIS Implementation

The adoption of the Alberta Health CHIIS program within Calgary Health Services was endorsed following careful consideration of the anticipated resource demands and program delivery benefits. It was expected that primary costs would be the result of initial computer and equipment purchases, staff training and data entry resources. Benefits to program delivery would be achieved through the use of CHIIS functions which include the ability to:

- maintain client demographic information;
- maintain client immunization information;
- maintain follow-up/tracking information;
- produce reports based on the CHIIS database;
- interface with the Provincial mainframe information system;
- produce consents and mailing labels; and
- allow for transfer of client information between offices (1).
With these costs and benefits expected, CHIIS data entry began in July 1994. For a multitude of reasons, a full technical review and pilot of the application was not possible prior to implementation. Predictably, a flurry of both small and large technical and information issues ensued. Technical problems were identified and solutions sought while procedures, protocols and CHIIS program functions were clarified with data entry staff. It quickly became apparent that there were significant functional problems with the operation of CHIIS on the wide area network established within Calgary Health Services.

**Technical Considerations**

Delays in program response time, due to the technology of the CHIIS application, were the most consequential. Data entry staff reported delays between five and 15 minutes in saving and printing a child health record. This severely restricted the amount of data entry that could be accomplished. Subsequent detailed technical analyses were undertaken and multiple solutions were implemented incrementally over a one year time frame to bring data entry response time to an acceptable level.

The first major intervention to improve CHIIS functioning was the removal of over 125,000 child health records that had been converted from the previous Central Records computer system used for the transfer of child health records in and out of Calgary Health Services. Incompatible data formats between converted and new CHIIS data were negatively impacting the system. Thus, the second CHIIS data base was formed.

Secondly, as the volume of CHIIS records increased the performance of the program diminished due to the technology of the application. It was thought that by reducing the number of records, the volume of information transmitted across the wide area network would be reduced and quicker response times would be realized. The removal of the converted records significantly reduced the number of CHIIS records, and subsequent mass data bases for school aged children were created on separate CHIIS systems.

Still, the functioning of CHIIS remained less than satisfactory following the removal of the converted data. To eliminate the problem associated with large volumes of data being transmitted across the wide area network, host computers and a communication package connected to the local area network were purchased and established for each remote computer. As CHIIS response time had been demonstrated to be at least ten times faster on the local area network, significant improvements in functioning over the wide area network were predicted and realized.

Further improvements in CHIIS functioning were obtained through changes to the central communications expressway software. Data entry is now accomplished at an acceptable, although not optimum, rate and user satisfaction with the technical functioning of the program is now high.

**Procedural Considerations**

Primary procedural issues related to the use of CHIIS within Calgary Health Services are the direct result of the need to use multiple data bases to ensure adequate program functioning. At present, the following nine data bases are in use: preschool; grades one, five, six, eight, nine, and ten; adoption data; and converted data. As years of birth are not necessarily discrete within data bases, it is often difficult to determine which data base to search for client information and to which data base to add new client records. Movement between data bases is a time consuming process requiring logging in and out of each CHIIS program, and all duplicate CHIIS records must be individually reviewed and deleted.

Another source of duplicate records is the electronic transfer of demographic data from the boards of education within the Calgary Region. On an annual basis the boards of education are approached and requested to provide electronic data for students enrolled in grades targeted for vaccination programs. This data is then used to update existing or create new CHIIS records. As an update requires a match of four student variables (first name, last name, date of birth, sex) many duplicate records are created where one or more variables are different. Listings of duplicates are then produced and individual records are reviewed and deleted.
Related is the problem that arises from obtaining data from three boards of education and having many children appear in more than one of these data bases. These data cannot be added to CHIIS as the actual school code cannot be determined until individual reviews are done.

The identification and deletion of duplicate records is essential to ensuring accurate data on each child health record. Inaccurate data can result in incorrect interpretation of vaccination status and unnecessary vaccinations for individual children. As CHIIS data is used to produce vaccination coverage statistics (external manipulation of data), duplicate records skew these results by producing inaccurate denominator and vaccination counts.

A second procedural issue arises from having a large number of staff responsible for data entry. As over 60 support staff perform CHIIS data entry with varied frequencies and volumes, it has been imperative to have initial and ongoing training and support given in a timely and consistent manner. Alberta Health provided some of the introductory orientation for CHIIS implementation with the remainder being provided in-house by a seconded staff member. Delays in CHIIS implementation and poor initial functioning of the program necessitated the development of staff and management committees to resolve issues related to CHIIS data entry and ensure the development and implementation of consistent policies and procedures across offices.

Verification of CHIIS data entry was initiated for 100% of records. Once individual staff demonstrate error rates below five percent for a period of four weeks, modified verification is adopted where data entry is verified for two month, eighteen month, and preschool records only. If an error rate of zero percent is obtained for three months, a process of checking 30 records per month is started and continues as long as 100% accuracy is maintained.

Additional training was provided by Alberta Health in preparation for the production of reports using CHIIS data bases. In light of the functioning of CHIIS on the wide area network (due to technical limitations of the software product that CHIIS was developed under), all reports must be produced centrally and forwarded to offices. As the performance of CHIIS is compromised when reports are run through either the local or wide area networks, an additional stand alone computer and high speed printer were purchased to produce and print reports from copies of CHIIS data bases.

A final training session regarding the use of CHIIS vaccination worksheets and mass vaccinations was provided in-house to office staff responsible for assisting with the management of school records. The use of CHIIS for this purpose negated the need to transfer paper records from Central Records to district offices and back to Central Records for the greater than 20,000 students in grades five and nine. As a complete review of vaccination status was required for each grade nine student, Central Records pulled each grade nine student record and entered vaccination data on CHIIS prior to the initiation of the vaccination program. This was done while students were in grade eight using a listing of students generated from the electronic demographic data transferred from the boards of education.

Another procedural issue related to the electronic transfer of school data is obtaining the data early enough in the school year to create the CHIIS data bases and to centrally print and send vaccination worksheets out to offices for review prior to the first vaccinations. Initial vaccinations are started in October in order to complete series during the school year, and accurate school data is not available from the boards of education until at least the end of September.

A final and ongoing procedural issue relates to ensuring the timely data entry of vaccination information for individual children so that up-to-date data is available on CHIIS at all times. With the initial poor functioning of CHIIS, this was a serious problem as data entry could not be accomplished at a sufficient speed. Priority data entry rules were established and it was made clear that the paper records had to be reviewed prior to proceeding with child vaccinations as the CHIIS record could not be assumed to be complete.

Improved CHIIS functioning resulted in increased speed of data entry but access to adequate computer time became a greater issue. Due to limited budgets, each office had only one primary computer for all general e-mail, word processing, and CHIIS work. As a result, it was impossible to accomplish required data entry within acceptable time frames. Requests for additional computers were approved and an additional data entry station was established in each office. District Manager computers were also made available to data entry staff when possible.
As the local area network assist for each remote computer can only be used for one computer, offices can only perform CHIIS data entry on one computer at any given time. Other computer stations can be used to look up information on CHIIS but data entry and mass vaccinations without the local area network assist are not feasible due to poor CHIIS performance on the wide area network. Ideally, a local area network assist should be budgeted for and implemented with each office computer.

**CHIIS Benefits and Tangible Gains**

The implementation of CHIIS was the first attempt within Calgary Health Services to provide a computerized child health record. To date, many positive outcomes have been achieved. Some of these include the following:

- replacement of a stand alone Central Records computer program used to track child health records transferred in and out of Calgary Health Services;
- immediate access by all offices to child vaccination and demographic data regardless of which district office the paper record is stored at;
- record location is identified easily to facilitate quickly obtaining the paper record;
- replacement of manual record transfer in and out procedures in offices;
- replacement of manual recall of children overdue for vaccinations through the generation of overdue reports;
- computer review of school vaccination status for ECS and grade one children (no need to obtain paper record for each child);
- data to support continued funding of the Early Maternity Discharge Program is entered on CHIIS and transferred by disc to Alberta Health on a quarterly basis;
- service delivery reports for postpartum families;
- newborn reports by office location;
- collection of statistical data related to infant feeding;
- electronic generation of records for school aged children to facilitate the delivery of vaccination programs;
- production of school vaccination worksheets;
- mass computerized vaccination record updating;
- quick identification of children inadequately vaccinated for the purpose of outbreak control; and
- the production of mailing labels based on client demographic information.

**CHIIS Limitations**

It is important to remember that CHIIS was developed by Alberta Health primarily as a computerized vaccination record to run on a stand alone computer. For this purpose, the program is generally acceptable, with a few exceptions specific to the use of CHIIS within Calgary Health Services. CHIIS has also been used for supplementary purposes with some successes (newborn and infant feeding data collection), and some failures.

One of the fundamental limitations of CHIIS is a result of the volume of clients serviced through Calgary Health Services. It has been impossible to use CHIIS to full potential given the fact that the program will not accommodate the volume of client records required and lack of data entry resources to accomplish this. At this time, only selected preschool and school aged records are entered on CHIIS (adult records are not entered). CHIIS can therefore not be used to provide data regarding the vaccination status of the population within the Calgary Regional Health Authority.

As all client vaccination records are not data entered, CHIIS cannot be used for electronic transfer of vaccination data to the provincial mainframe information system or to track clients for follow-up. A manual follow-up system has been maintained for each of these purposes.

CHIIS has not been used within Calgary Health Services to produce vaccination consents for school aged children as they do not reflect agency consent policies and procedures. Dual consent cards for parent and child are issued manually to school aged children.
Immunization coverage reports available within the CHIIS program have not been functional to date. To obtain required coverage rates, external manipulation of the data has been completed using other statistical programs. This is a time consuming and costly process requiring specialized personnel with computer expertise.

In using CHIIS data to review birth and infant feeding information, it is not possible to accurately report retrospective information. As reports are produced according to record location, when a child transfers from one office to another, the record location changes. Therefore, you can only produce birth data or summaries of infant feeding practices for a population based on the current location of the child health record. As CHIIS is now used within Calgary Health Services to collect this data, a procedure of entering a separate geographic code to specify where the family resided at the time of the infant’s birth has been implemented. This code is not changed with transfers to other offices. External manipulation of this data is required to produce the required statistical reports.

All reports of CHIIS data are provided in individual or summary formats. It is not possible to use CHIIS reports to generate relational data. For example, a report can be produced detailing the number of teen mothers and another report the number of mothers breastfeeding their infants, but a report of the number of teen mothers breastfeeding cannot be produced. External manipulation has been used successfully to provide relational reports.

CHIIS does not have the capacity to track all of the child health information previously collected and currently required. This has compelled the use of multiple data collection and data analysis procedures and programs to ensure data collected using a single system in the past continues to be collected for comparison and program evaluation purposes.

Future Considerations

An investigation of the information system requirements within Calgary Health Services is in progress. In conjunction with this review, the continued use of CHIIS is being evaluated. Although the costs of CHIIS have been high and limitations have been encountered, many benefits and tangible outcomes previously not available have been realized.

As CHIIS is a provincially developed program and has the support of Alberta Health, most regions in Alberta are using the program. This commonality with other regions has proven valuable in identifying related needs and problem solving related issues. Yet, while many needs and issues are mutual, many are specific to individual regions and populations.

While it is wise to maintain a review and analysis of alternative client centered programs that could be adopted or developed to better meet the information needs within Calgary Health Services and the Calgary Regional Health Authority, a decision to replace CHIIS needs to be carefully considered. Another system will require a full technical review, the development of a conversion and implementation plan, technical and equipment support, staff orientation and training, related policy and procedure development and a period of skill development. This step will be considered only if a program is found which can meet the needs of multiple goal areas and provide a shared data base within Calgary Health Services.

References

Internet Applications - 3

Chair: Tom Abernathy
Information Superhighway or Information Traffic Jam for Health Care Consumers?

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Keywords: World wide web, Healthcare information, internet.

Abstract

The phenomenal development and growth of the information superhighway over the past few years has brought with it an ever increasing number of sites associated with health care. At the same time community access to the internet and multimedia technology has allowed greater access to health care sites by consumers wishing to find health care information relevant to their needs. The internet has great potential for improving the health care knowledge of the community, especially in remote areas or in parts of the community that have limited access to community health infrastructure. However, most of the current development of health care sites has focused on the needs of health care professionals rather than consumers. Indeed with the volume of information available over the internet it is easy to spend hours browsing through a maze of sites with information that is often fragmented, incomplete or only assessable with a password. Once a relevant site is located the information is often presented as vast amounts of text with possibly some graphics. It appears little consideration is given during the development of web sites to the actual presentation of the information. For the full potential of the information superhighway to be realized in relation to health care more consideration should be given during the development stages of web sites to how the information is presented and how to make access more streamlined.

1. Introduction

With the development of the World Wide Web (WWW) the internet has become readily accessible for a large part of the community. The introduction of Web browsers such as Netscape and Mosaic have taken the internet from a text based communications tool to a system which allows people to receive information graphically (text, pictures, sound, video) from sites around the world (Flower, 1995). Added to this has been the development of "search engines" which allow the user to identify Web sites that may contain information relevant to their needs. Increasing numbers of health care related internet sites are being developed and are readily accessible to anyone via the WWW. These sites cover a broad spectrum of health related issues, and allow the sharing of information between health care professionals. This paper will examine some of the potential problems health care professionals and consumers may encounter when attempting to access health care sites and the difficulties associated with determining the validity of the information obtained. Secondly issues related to the development of Web sites will be reviewed and ways in which developers can improve the design of health care sites to better serve the health care community will be outlined.

2. Finding what you want

Health care has certainly not been left off the "information superhighway". The numbers of health related sites is vast with the origins of the sites varying from educational institutions, research institutes, commercial ventures to private individuals. These sites provide a significant health information resource that can be accessed by anyone with the skill, time and a connection. The potential of this resource to help the community become better informed about their own health and disease management options is significant. However, for this potential to be fully realized, problems associated with accessing relevant and reliable sites must be overcome.
The world wide web is a mine of information, however finding relevant information can often be a time consuming and frustrating task. Until recently it has been relatively difficult to search for information on the internet, but software tools or "search engines" are now available to assist in this process (Kassirer, 1995). These tools have made searching for specific information a simple and fruitful task. A problem arises here because of the efficiency of some of these tools and the immense amount of information available via the internet. The number of "hits" identified by these tools is often large and it may be unclear from any summary how relevant the site is. To demonstrate this point, several search engines were used to identify sites on a variety of common health related topics.

<table>
<thead>
<tr>
<th>Search engine</th>
<th>Diabetes</th>
<th>Arthritis</th>
<th>Asthma</th>
<th>CAD</th>
<th>Heart attack</th>
</tr>
</thead>
<tbody>
<tr>
<td>Webcrawler</td>
<td>1851</td>
<td>1423</td>
<td>936</td>
<td>10124</td>
<td>29602</td>
</tr>
<tr>
<td>Lycos</td>
<td>9435</td>
<td>4987</td>
<td>3843</td>
<td>38163</td>
<td>86073</td>
</tr>
<tr>
<td>Magellan</td>
<td>5102</td>
<td>2874</td>
<td>2064</td>
<td>32410</td>
<td>62673</td>
</tr>
<tr>
<td>Excite</td>
<td>71413</td>
<td>60659</td>
<td>37450</td>
<td>512250</td>
<td>1367317</td>
</tr>
<tr>
<td>Hotboot</td>
<td>86098</td>
<td>49327</td>
<td>46574</td>
<td>11434</td>
<td>104733</td>
</tr>
<tr>
<td>ALtaVista</td>
<td>40000</td>
<td>20000</td>
<td>10000</td>
<td>20000</td>
<td>100000</td>
</tr>
</tbody>
</table>

Numbers of "Hits" for each disease at each site  
(CAD= Coronary artery disease)

As can be seen the number of "hits" for each topic varies with the search engine used. Searches can be refined with advanced search options but even when this is done the dilemma of a large number of sites with potentially useful information remains. With such a large number of sites how is the user to determine which will be the most relevant to their needs? Browsers such as Net scape allow reasonably rapid access to identified sites, however accessing each site individually to check for relevant information is a very time consuming and potentially costly exercise with no guarantee success. Once a site is accessed the information may be inappropriate for the lay person and may be aimed at a medical professional or researcher.

No doubt all internet users have suffered the frustration of waiting for an what seems a long time for a reply. Depending on the "traffic" on the line at the time access may be slow or the user may be timed out. Another problem may be the site is no longer available or has moved to another location without all the links being updated. To be successful at gathering relevant information the user often requires patience, persistence and a willingness to experiment (Tomaiuolo, 1995). Because the information is so vast and potentially difficult to navigate the user may become frustrated and move on without finding the necessary information (Galer, Haker, Ziegler, 1992).

Another pitfall of the present system occurs when a site is located during a search that, on summary appears to offer the user a useful source of appropriate information. However when the site is accessed it does not offer much in the way of information alternatively it may be an advertisement or a link to a page which will cost money to fully access or is selling books related to the area rather than providing on-line information. While many sites are free to access there is an ever growing number of commercial sites aimed at making money.

3. Reliability of on-line information

Because of the nature of the internet, sites can be developed by anyone, the accuracy of the information and advise on health care may vary depending on the knowledge of the developer (Kassirer, 1995). A strength and potential weakness of the Web arises as a result of the ease at which anyone can publish anything they want (Shotsberger, 1996). While many sites do provide reliable information, there are others that are less reliable. Currently there is no effective means to ensure all health care sites provide accurate and reliable information to the user.
4. Community Health Education

If we consider the Web as an educational tool for health care consumers, any learning that occurs with the current arrangement relies on the user's ability to access sites, follow links and absorb information passively. What is considered a well-designed Web site may vary between individuals; however, there seems to be little attention paid during development to the effects of the design on learning. This may be a result of the ease at which Web sites can be developed by anyone using one of the new Web authoring tools. It is not uncommon to come across sites that seem to utilize all the possible features of presentation simply because they are there rather than for any useful educational purpose. There are many high-quality health-related sites; however, this cannot be said of all the Web sites currently available.

To improve the effectiveness of the Web as a learning tool for the community in relation to health issues, it is essential that developers take into account the user's needs and not just how they can utilize all the features available.

5. Legibility and readability

Despite the graphical abilities of the WWW, text remains the major manner in which information is represented. The delivery of text generally requires the user to read via a computer screen (unless the information is printed prior to reading). Thus it is important that text is delivered in a fashion that is legible and readable. Little research exists in relation to reading from computer screens and how this may be optimized (Muter, 1996). There is general agreement that any text delivered must be at the minimum legible if any learning is to occur. Legibility varies depending on several factors; type face used may play a significant role in the legibility of Web documents (Sans-Serif type may be more legible when displayed on a computer screen). Text in all upper case should be avoided (Wheildon, 1990). Other factors that may contribute to the legibility of text include its size, colour and interline spacing. Backgrounds of different colours and styles are readily available, often the background itself prevents overlayed text being easily read. Coloured or patterned backgrounds may make the site look like a professionally developed advertising page but do little for improving the text legibility. Certainly it is not uncommon to see Web pages with dark backgrounds and dark text which is difficult to read. Readability relates to the attributes of the text as a group of words or sentences. Readability gives an indication if the text is written in a manner which can be easily understood by its target group (National Cancer Institute, 1991). When writing a Web page it is important to determine who the target audience will be and use appropriate language that group will understand.

6. How much text?

According to Nielsen (1996) few users bother to scroll any further than the information that appears on the screen when a page is loaded. If there is a long section of text, the user will probably only scan the introduction and move on. Web pages should therefore be limited in length to minimize the need for scrolling through text. This can be achieved by the organization of information into short paragraphs and lists with appropriate links to subsequent short pages of further information (Shotsberger, 1996).

7. Navigation links

One feature of the WWW is the ability to provide navigation links between documents. While this feature allows ready access to related pages, excessive use of links, such as often seen with multiple links in one paragraph, it is more likely that the user will scan the page and ignore what could be a valuable link (Shotsberger, 1996). When pages are developed navigation must be obvious to the user to allow ease of movement through the site. Navigational features used must be consistent and reliable, with links checked for currency at regular intervals. There is nothing worse than exploring a web page and following a link that is no longer available. (Nielsen, 1996).
8. Using graphics

While the use of graphics may enhance the learning that occurs and make the page more visually appealing, developers should always remember that images are slower to download and may add to the expense of using the Web for a health care consumer. It may be better to minimize the use of logos and other images that appear on each page and only use graphics that are essential to the message. Sound and video files may also be made available, however such files often large and take significant time to download. A user may become bored with the wait and move on.

9. Summary

The internet has already become an extensive source of information for health care professionals and consumers. The exponential growth of the internet can be at least partially explained by the advent of the WWW and the ease at which this protocol allows users to access and add information (Waldrop, 1994). However, the viability of the internet as a useable source of health care information may be limited by the volume of information available. Flower (1995) suggested, "a technology that can bring all the information from everywhere to your computer is useless unless it can also help you find what you really want". Search engines that allow advanced searching may make accessing specific information less time consuming. A specific search may be possible but does not help the user determine whether information at the site is authoritative and reliable. Currently any individual can create their own site and electronically publish information that may be highly questionable, there is no effective mechanism for rating the quality of health related sites. Once accessed Web sites should be presented in a form that encourages minimizing sources of frustration for the user and presents the information clearly and logically. People responsible for creating and maintaining health care related Web sites must consider the audience they are targeting to ensure all text presented is readable and legible. The design should allow for easy navigation through the site and back to the users original starting point. Excessive use of links will detract from the site, any links used must be relevant and current, this may mean it is necessary to occasionally check the links are not outdated and still work. The potential of the internet to communicate health care information to the general community and enhance sharing information with other health care professionals is great. However there remains many problems that must be resolved to ensure the information is accessible and useable.

References


Abstract

Healthcare reform, economies of scale, advances in diagnostic technology, and the movement from hospital-centered to community-based healthcare, have motivated the consolidation of laboratory services and the development of the regional Laboratory Services Organization (LSO). Virtually overnight, the "full service laboratory in every hospital" paradigm has been replaced by a regionally-optimized "laboratory without walls" concept. The LSO would ideally disperse its components from the points of care, to regional laboratory "factories", optimizing both services productivity and testing turnaround time.

Accomplishing the LSO requires dramatic shifts in the information technology infrastructure that enables the ordering, performing, and reporting of laboratory tests. Among the required changes are: selecting systems that enable inter-entity and not just intra-HIS integration; interfacing and quality control of near patient testing devices located anywhere care is delivered; implementing communications, data, and security standards; finding LIS-like products that deliver work process, instrumentation control, and specimen management functionality at the many points of testing, not just in the hospital lab, providing an "enterprise-wide", physician-coupled test ordering and results reporting interface; enabling inter-facility order, specimen, and results movement; planning, funding, implementing, and maintaining regional IT facilities and services; and addressing a heterogeneous legacy information systems environment, seamlessly and economically.

We summarize the work we have done designing LSOs, articulating their IT requirements, and working with industry to develop solutions. The solutions for "integration" are taking the form of "meta-interface engines", with intelligent routing of both protocol and non-protocol transactions, interconnecting existing institutional, clinic, and practice-level systems, with optional repositories and data warehouses.

1. Introduction: Understanding the Business Issues

It is commonplace in the United States and increasingly frequent in Canada, that healthcare organizations are considering and forming regional entities (integrated delivery systems) to deliver healthcare services. Healthcare reform, decreasing public funding, the advent of managed care, and the recognition of the value of an integrated healthcare system motivate the formation of institutional networks, and the consolidation of locally-suboptimal services.

One area of particularly intense regionalization activity is that of developing shared or at least regionally coordinated and rationalized laboratory services. The rethinking of laboratory services on a trans-institutional basis is driven by many factors, among which the following are particularly important:

- In the United States it was recognized that the DRG-based funding turned the laboratory from a profit center (as it was under fee-for-service) to a cost center, and that controlling the cost of these services was essential to maintaining institutional profitability.
Managed care has intensified the interest in reducing unnecessary utilization and optimizing laboratory performance to cost ratio.

In Canada, the combination of the shrinking healthcare budget, and pressure or directives from government to organize and optimize the healthcare system on a regional basis, have provided the motive force towards the realization of economies of scale.

In both countries, the new laboratory diagnostic technologies that have become available, the recognition of the need for fully integrated clinical information to enable competent diagnosis and patient management, and the recognition of the clinico-strategic value of the accessible longitudinal patient record have dictated innovative thinking. Not only have the rules of the game been changed, but new cards have been put in the deck, including point-of-care (POC) testing devices, near-patient satellite testing facilities, new testing technologies, highly capable and high-volume instrumentation, and robotics, all with wireless connectivity.

The rethinking of the laboratory services component healthcare system is leading to real re-engineering: not local streamlining, but genuine innovation and radical restructuring of laboratory services. This rethinking has "front-burnered" interventions such as the establishment of regional roboticized laboratories, the implementation of highly automated local core labs, the development of regional centers of excellence for esoteric testing, the move to alternate site testing (including point of care and near patient testing), the formation of regional laboratory services administrative entities, the implementation of sophisticated, efficient, specimen acquisition and transportation systems, and dramatic re-organization, cross-training, and optimization of the roles and deployment of laboratory professionals.

The Laboratory Without Walls will have the following major characteristics:

- testing will be performed at a location that ensures the optimization of the value of lab testing for the care of the patient. POC testing will play a significant role as turn-around time (TAT) can be minimized. The high variable costs of POC devices will be offset by their low fixed costs and by the value of the immediate results. POC results will be captured via wireless connections.

- satellite near-patient testing facilities will exist now that the quality control, operation, and connectivity issues associated with these facilities have been addressed. The need for rapid TATs drives their existence. Satellite facilities will be fully-integrated via the enterprise IT system.

- the classic laboratory will down-size and become highly automated, with specific labs in the region becoming responsible for esoteric tests, with specimens transported to them via a tightly-monitored, IT-assisted specimen transportation system.

- tests with longer TATs will be processed at on-site or off-site regional and possibly national robotic laboratory testing centers, with full connectivity with the above, and with appropriate extensions of the specimen transportation system. Economies of scale will be the drive here.

Laboratory testing will no longer be localized, but will be distributed to optimize total patient care cost, and then the cost of testing. Furthermore, there will be continuous reconfiguration of the location of testing as technology and other factors change.

2. The Role of IT

The innovators of laboratory services have recognized the mission-critical importance of information technology to the implementation of the rethought laboratory services organization. Not so long ago, the Community Health Information Network (CHIN) was a technology looking for a business rationale, and many CHINs have had hard times lacking this rationale. For the laboratory services rethinkers, the CHIN is the essential utility to enable the re-engineered service.
Beyond the obvious need for an inter-entity information transport mechanism, though, the true and full nature of the IT requirements has at best been perceived "through a glass, darkly".

Here, we look beyond the basics: the need for an inter-entity CHIN and for capable local or shared Laboratory Information Systems (LISs). We also ignore the supportive services (such as the enterprise-level IS department and the enterprise CIO) that are essential to implement and maintain the panopoly of technologies, the organizational structures necessary to deploy these services, and the re-engineering of work processes required to maximize the value of the technologies. The focus of this article is on understanding what is required of the systems that will utilize the CHIN to operationally integrate disparate information systems to provide the infrastructure for re-engineered laboratory services.

3. Understanding the IT Requirements of the Laboratory Without Walls

The most abstract statement of the IT requirement is that we must create a trans-entity laboratory information system with point of care ordering and results reporting that is integrated with other information resources required for clinical decision-making, and patient care, operational, and financial management.

The major characteristics of an IT solution that addresses this requirement are:

The solution must address the multiple, heterogenous "legacy" LIS environment.

The typical regional situation involves in the range of 5 to 15 or more participating entities (e.g., hospitals and clinics that provide laboratory services), and one or more commercial laboratory providers, each having a different LIS or substantially different implementations of a specific LIS.

Although the selection of a single LIS with multi-site capabilities would be a strong technical/economic preference, this will generally only be a consideration in tight consolidation ventures, wherein laboratory services (and other or all components of the healthcare delivery system) are merged or under common governance, and/or in those situations when all LISs are near the end of their life-cycle.

Even clients with the same vendor may have substantially different implementations of their LISs. Specific LISs allow a very high degree of customization, and individual implementations of these need to be considered as virtually different products.

One implication of this is high interfacing costs, when, as often is the case, each interface is treated by the vendor as a separate development. This interfacing cost dominates the cost side of the business case.

Even clients with products that restrict customization will generally be implemented with significantly variant data definitions, test menus, procedures, normals, etc., requiring a significant investment in the development of data standards.

To minimize interfacing and support costs, all LISs of the same vendor must be brought up to the same version, and required missing modules must be acquired. Note that this upgrading may require a significant investment in hardware (e.g., replacing Vaxes with Alphas). This upgrading cost is the second most important component of the IT cost equation.

Often, each participating entity will have different vendors' products addressing their other IT needs: e.g., differing HISs, OE/RR packages (Order Entry, Results Reporting; these may be separate packages), ADT, and Billing/Finance systems. Best-of-breed strategy sites will have several different vendors' products.

This implies the development of many interfaces, as the full solution may require interfaces to the LIS, OE, RR, ADT, and Billing systems.

The importance of the enterprise-wide connectivity to OE and RR interfaces is yet another argument for the adoption of a single enterprise-wide OE/RR system that also provides a consistent user interface invariant of locus of care.
Few, if any, participants will be willing to replace their existing systems.

Although wherever possible (particularly in those situations where a merged entity is the resultant configuration, and for reasons of economics and simplicity) the minimization of the number of different LISs should be encouraged (primarily to reduce the technical and support team complexity, and support costs), in most instances this is not acceptable to the participants.

Labs with outdated and/or limited functionality LISs, with significant maintenance problems and/or problematic support, and/or where significant re-implementation is required, are particularly good candidates for conversion to a "common" LIS.

Many regional entities/networks will adopt a "mosaic" lab services architecture (tests are performed at "centers of excellence"), and/or provide a high-volume central service. Consequently, tests may be processed at any participating lab, and/or near or at the point of care, and/or at a central facility.

There are many possible "rules" for the choice of processing site: specific tests may always be performed at a selected site, some tests may be processed at the originating institution's (the institution/entity from which the order originated, i.e., the hospital ward or the ambulatory care center office) lab during certain times/situations (e.g., specific times of day, or when equipment is serviceable, or during vacation periods, etc.) and at another site during other times/situations. Often, an order may be split to be processed at several sites (time/situation variant). There must be excellent systems support for rules specification and maintenance.

An implication of this is that an excellent specimen identification, shipping, and tracking system, employing computer-readable (e.g., bar code) labeling, interfaced to the LISs, must be part of the solution.

Another implication is that near-patient device connectivity is crucial.

Test requisitions and results (and specimens) are required to flow among institutions in a reliable and transparent manner.

Orders created with the originating institution's OE system, must be registered at the originating institution's LIS, and passed to one or more processing institutions' LISs.

Results and status information must flow in the reverse pathway, from the processing institution's LIS, being registered at the originating institution's LIS, and passed to the originating institution's RR system.

Specimens originating at any site, must be acquired, identified and registered, split, and shipped, moving to any processing site, while being tracked throughout.

The advent of the clinical data repository and the data warehouse require their integration. This is particularly important as results reporting will likely be provided via the clinical data repository.

Each participating institution and the enterprise as a whole must be able to track and report its "processed here" and "pass through" workloads.

Even if a central repository is created for results, the individual LISs' management/operational databases must be updated to support management reporting. It is possible that the use of a central repository and the existence of adequate management reporting software based on this repository, will eventually allow the relaxation of the requirement that orders and results reports be registered at the individual LISs.

In looser regionalization ventures, a repository may not be a viable solution, as strict ownership, control and confidentiality of information will be a requirement.

A "seamless" and "transparent" information system is required to enable this.
No ordering provider at any participating entity can be affected by the restructuring of lab services, other than by the potentially slower turnaround of tests processed remotely.

The IS environments of the participating institutions/entities will not, unless desired, be affected by the lab restructuring, other than the interfacing of specific packages to a "meta-Interface Engine" (an interface engine that operates at the enterprise/regional level).

Data standardization is essential, including ultimately: common test definitions and menus, common testing standards/normals, common procedures manual, etc.

The IT solution for labs must be extendable to other services suited to regionalization (e.g., Diagnostic Imaging, Nutrition, Pharmacy, Specialist Consults, Materials, etc.)

The solution cannot be unique to labs, requiring replacement/rewriting to serve the needs of other ancillary services rationalization.

At least part of the cost of the solution must be attributable as infrastructure for other such ventures.

All origins for orders and destinations for results must be able to be included under the same overall solution.

Orders must be able to originate at and be returned to any point of care or work, whether in the hospital, ambulatory care clinic, provider's office, etc.

Although, optimally, ordering would be via an enterprise-wide OE/RR capability, the practical situation is the existence of many OE/RR systems (i.e., differing interfaces in the provider's office, in the ambulatory clinic, and in the hospital).

Preferably, the solution will not "take sides" with any of the existing LIS/HIS vendors, but will be perceived as an "open" and "generic" solution.

The selection of an LIS vendor's integration solution has been and may be a negative in a situation where that vendor's LIS is not favored by some or all of the participants.

The solution must fit well with the participants' IT strategies.

The solution must append to or be an extension of existing IT strategic plans, not require their realignment, must be an affordable component of the cost of regionalization, and must be supportable by an "economical" enterprise-level IT service organization, if such is desired.

The solution must not require the adoption of a unique patient identifier by all participants.

Although, ideally, in the case of consolidations, all participants should adopt a common unique patient identifier for record linkage purposes, the massive change to accomplish this must not be a barrier to regionalization. In the case of networks of competing labs, this solution awaits higher-level resolution. Therefore, the solution must preserve the association of the originating institution's patient/specimen identifier with the order/specimen, and must support the mapping of institutional identifiers to an enterprise unique identifier to enable the maintenance of a regional longitudinal patient record.

The solution must address the issue of vulnerability, i.e., being the single point of failure for lab services.

High performance, reliable, redundant, and fail-soft systems and communications links, data protection and integrity preservation, and disaster recovery are essential components of the solution.

Security must be adequate to address participants' standards and requirements.
The realization of the full solution will, by the very nature of its complexity and magnitude, requires a comprehensive, locally-customized array of laboratory-related and IT advisory services, information and communications technologies and network (local and wide area) services, implementation and maintenance services, with a set of financing options (including price by usage).

It will be very rare that all of the expertise and resources requirements can be addressed from within the participating institutions.

4. The Types of Solutions

The purpose of this article is the full comprehension of the problem. However, the types of possible solutions are predictable, even though, at the time of writing, none is available "off the shelf":

Homogenize/Integrate

All hospitals abandon their separate LISs and invest in a single, shared, multi-institutional product. This may have distributed hardware with truly integrated software, including an integrated database, or it may have a central system with links into the individual labs.

Stay Heterogenous/Interface

The material above describes the characteristics of this solution. The technology required is essentially that delivered by the interface engine companies, augmented by "intelligent" routing (rule based information flow to and from sources and destinations), enterprise patient index with record identifier synonym support, a specimen shipping and management package, and several other capabilities to address non-HL-7 interfacing). It is also possible that e-mail-enabled workflow automation systems can be the information transport mechanism, and the use of a "dummy" LIS as an information-routing tool is also possible.

The clear implication of this article is that the latter will be the prevalent solution as the dream of regionalization of laboratory services becomes reality.

Our experience base is currently in excess of 50 such ventures, many with more than 10 participating entities. We have found that the IT requirements stated above are consistent and mission critical. Our review of interface engine vendors, LIS vendors, CHIN-providers, and integrators has uncovered only partial solutions. The primary gaps relate to the problems of "intelligent routing", and the complexity, cost, and time requirements associated with interfacing to existing systems. Unfortunately, the lack of a comprehensive solution has not impacted the sales efforts of some "solution providers", and disappointment is not an uncommon deliverable.

5. Acknowledgments

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Reference

Lowering Physician Hospital Resource Consumption Using Low-Cost Low-Technology Computing

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Abstract

Anderson Area Medical Center physicians have been provided disease and procedure specific profiles of their practice experience for more than five years. For four years, physicians were provided reporting, in a variety of formats, detailing their clinical outcomes and consumption of hospital resources in treating patients with acute myocardial infarction (AMI), pneumonia, cholecystectomy, stroke, congestive heart failure (CHF), and total hip replacement. For the past eighteen months physicians have been provided a uniform format of monthly physician-specific reporting for stroke, AMI, pneumonia, diabetes, CHF, cholecystectomy, total hip replacement, newborn delivery, angina, and hernia repair. Using only a modest PC platform with database, word processing, and graphics programs operating in a DOS environment, an effective disease/procedure reporting program is provided to medical staff with 3 person-days of effort per month.

Education-based physician practice reporting is effective in encouraging more resource-efficient decision making on the part of medical staff members. Average LOS and total charges can be reduced significantly by providing physicians with profiles that show them their relative rankings with peers for several outcome and resource variables.

Actual aggregate reductions in average total charges for each of three groups of patients profiled following educational reporting to physicians were $203,680 (AMI), $220,296 (pneumonia), and $146,832 (hip replacement). Total benefit for these three educational reports was $570,808. If educational effects persist for a year in the physician groups, the annualized estimate of aggregate charge reductions for 390 AMI patients, 483 pneumonia patients, and 52 hip patients is $1,568,644. Cost savings to the hospital would be near $706,000.

1.0 Introduction

Physicians receive approximately 20% of health care dollars, but physician decisions create 80% of the costs of medical care [1]. To effect significant changes in the use of expensive medical resources while preserving optimal outcomes for patients it has been proposed the modification of decision making behavior is essential for success. The literature is replete with evidence that physicians are quite responsive when provided with a variety of data, be it the results of randomized clinical trials, financial information, or details about variations in physician practice patterns.

Several authors have reported success in providing physicians information about the cost of services at the time of ordering. Cummings [2] described a study where 36 second and third-year residents and 23 clinical faculty were asked to review four case studies, each describing ambiguous symptoms and to indicate on an attached order form the tests they would order for each patient. Physicians randomly assigned to the experimental group, received a test order form on which the price of each test was provided. The control group was given the same order form without pricing information. Those physicians provided with pricing information, ordered total tests costing 31.1% less than those ordered by physicians not provided with pricing information.

James [3] reports that it is not directly possible to determine if inter-physician variation in use of resources is appropriate or not. He provided blinded study results to hospitals and physicians and physicians to act on as they
saw fit. He reported very high inter-physician variation in resource utilization in every clinical area for patients receiving Transurethral Prostatectomy. The only action taken after the initial study was to share confidentially with physicians this variation data and nine months later to make an assessment to determine if any impact was made on resource utilization. Average Length of stay (LOS), as but one measure of utilization, dropped 37% from 4.40 days to 2.83 days.

Lamas [4] found that the publication of definitive study results in and of itself was sufficient to change physician behavior in terms of drug and test ordering, confirming that physicians are interested in doing excellent work and will read major journals to stay clinically current.

Zieve [5] found that providing physicians with physician-specific ordering information, as reflected in drug-specific charges, produced large savings for a 500-bed hospital. Providing physicians with charge information resulted in savings of $179,000 in the first year on NSAIDs alone and savings of $119,000 for CCBs.

An experimental-control group study [6] was carried out at Anderson Area Medical Center in which the experimental variable consisted of a one-time exposure of physicians to clinical and financial specifics regarding their individual treatment and management of pneumonia patients. It was found that providing physicians with specific information about their practice behavior resulted in these same physicians using fewer hospital resources as expressed in total billed charges and Length of Stay (LOS). The experimental group's 6.8 days was significantly lower than the control group's 10.0 days. During one six-month period the experimental group had a statistically significant lower mean charge ($5,988) than the control group ($10,051). At the same time there was no compromise in outcomes for patients as measured by mortality, readmission rates, or infection/complication rates. The improvement in resource utilization was observed for two years following the provision of practice specific data to the experimental physicians.

2.0 Methods

2.1. Background

A research group was formed at AAMC in 1987 to develop a severity-adjusted physician education system. This system used a hybridization of genetic algorithms, neural networks, abductive-inductive methodology, case modelling, and complex in-house written programs along with statistical packages, word processing, and graphics generators to produce physician-specific reporting. The statistical results were most impressive and external observers cited the predictive capabilities as being among the best available [7]. Significant changes in physician behavior were reported [6].

In 1992, all but one member of the research group relocated to another state to continue development in a proprietary domain. The group has continued to enjoy significant success as reflected in its receipt of the 1994 Healthcare Technology Innovations Award for a neural-network based 'heart attack' predictor.

The technologies and expertise required to develop and maintain high-quality severity-adjusted programs are not available in most hospitals and the acquisition of commercial products and/or expertise can be exceptionally expensive. Some commercial products require hospitals to hire nurses to do extensive chart review of all charts and this, coupled with licensing fees, can drive annual costs to over $500,000 for a severity-adjusted reporting system.
2.2. Development

Believing it possible to effect significant behavioral changes in physician-practice behavior without using the complex technologies accessible only to highly-trained individuals, we developed a new physician-specific reporting format. It incorporates graphical concepts of statistical process control (SPC), uses widely-disseminated inexpensive software, requires no chart review or coding, and makes a combination narrative and graphical report available to physicians at a rather modest cost. Only moderate technical skills are require to produce reports.

The data used as input for the Physician Practice Performance system is derived from the Medical Record Abstract System (MRA) and the UB92 billing files. The hospital maintains the MRA and billing systems on an AS400 operating with Ibax software products. An extract program, written in RPG, is used to obtain 11 data elements for each patient, for a selected time frame, from the MRA and UB92 and writes them to a disk file. PC Support is used to download this file in an ASCII delimited format. 149,000 in-patient episodes have been downloaded since 1988.

Like its more complex predecessor, the present Physician Practice Performance (PPP) system operates on a PC DOS platform (486-50) and uses this download file as its only data source. A new download file is obtained twice a year to update the expanding local PC patient data base. Inherent systemic delays in final billing of accounts results in a 60-120 day lag before many records will appear on the MRA. Because of this lag, new download requests will include a time frame beginning a year prior to the date-of-request to obtain records previously not captured in download files.

The usual UB92 demographic and financial data elements are downloaded along with several dozen elements from the MRA. The extract program groups financial data into categories including lab, pharmacy, radiology, respiratory care, total ancillary, and total patient charges. It also obtains financial class, payor codes, and admit and discharge codes. The Medical Records Department has been committed to a deep level of coding and has been providing robust ICD-9 coding to the MRA for eight years, knowing the deeper coding was being used for research and physician-practice reporting. The coding has included up to fifteen ICD-9 diagnosis codes and up to ten ICD-9 procedure codes. In addition, other data elements profile hospital infections, complications, blood utilization, use of special care units, OR and post-op mortality.

The ASCII download file is imported into an R-Base table. R-base is a relational data-base program capable of handling tables with millions of rows and tens of million of cells in a single table. R-Base provides some 'hard-wired' statistical functions that are user friendly as well as allowing one to write programs of immense complexity, if desired. In our case, R-Base is used as a data-handler and very simple programs were written to perform statistical calculations.

For the physician reporting described in this paper, R-Base is used to calculate physician-specific and hospital-wide rates for 1) complications, 2) infections, 3) mortality, 4) readmissions, per-diem charges, 5) charge ratios, 6) use of consults, 7) LOS, and 8) six charge totals (total, ancillary, pharmacy, respiratory, lab, radiology). It is also used to calculate demographic variables including sex, age, and race.

The R-base programming used is little more than a series of chained macros within the province of those just beginning to develop their computational skills. We have used Word Perfect 5.1 to write all of the R-base macros. Word Perfect proves a robust editor for writing program code. Word Perfect documents saved as DOS files are accessible to R-base as source code without further modification.

2.3. Report Structure

Each physician report includes a title page, a two-page narrative text containing comparative statistics, a one-page table providing inter-physician comparisons for eight variables, and three final pages, each containing three pareto charts depicting physician performance for a key resource or outcome variable.
2.4. System Structure

Physician reporting is created using a PC 486-50 with DOS 5.0 as its operating system. R-Base 4.0, Word Perfect 5.1, and Harvard Graphics 3.0 are used to generate the narrative and graphical components of the reports. PC-Support is resident to provide access to the AS-400 mainframe.

Report components for each disease or procedure are kept in separate subdirectories on a hard drive. Components are reused each year when an updated disease report is produced. We find that keeping files and documents in separate directories make long-term maintenance much simpler.

Word Perfect 5.1 files include separate ones for 1) report title page, 2) two-page physician narrative summary (a primary merge document with merge fields), 3) a physician-specific variables table, 4) physician cover letter (a primary merge document with merge fields), 5) name/address file for letter generation (a secondary merge data file), 6) resource/outcome data file for loading narrative reports (a secondary merge data file).

Nine Harvard Graphics files are maintained for each disease with each file containing a single pareto chart. These are readily updated and consume very small amounts of disk space.

R-base command files and program files are kept resident in the R-Base main directory. Disease- specific extensions are used for file names so as keep them identifiable for a particular disease.

2.5. Procedure

R-base macros are adjusted for new date ranges prior to generating data for an updated report. The data generated is written to a disk file, reformatted with Word Perfect and printed on paper. The data is then keyed into the secondary merge document for the narrative report and into the variables table. The physician name/address file is updated for the cover letters. Merges are completed for the narrative report and the cover letter. The Harvard Graphic pareto charts are updated with the new data values. Individual physician values are highlighted in color. The title page date is changed and printed. The title, text, and graphics are assembled and three-hole punched. These are then mailed to the physician with the signed cover letter.

3.0 Results

3.1. Acute Myocardial Infarction

On February 7, 1994, twenty physicians treating AMI were mailed the report containing the narrative text, tabular display of data profiling inter-physician variation for seven indicators of outcomes and resource consumption and six pareto graphs displaying physician ranks for mortality, complication rate, infection rate, 31-day readmissions, average total charges, and LOS. Physician-specific data was provided for all the physicians but was blinded for identity for all but the recipient.

Additional histograms were provided summarizing the physician group experience with AMI. Hospital mortality comparisons to HCFA national data and the data from the National Registry for Myocardial Infarction were given. The use of thrombolytics, heparin, aspirin, beta blockers, calcium channel blockers, and nitrates during the early phases of treatment was summarized as well.

The first 134 patients treated after the reporting was provided (3-8-94 to 8-7-94) were profiled. A similar-size (131) group of patients treated just before the reporting was received by the physicians (11-1- 93 to 2-7-94) was profiled. The results are shown in Table 1. If this level of charge reduction was annualized, the positive effect on total charges would be $592,800. 2 outliers were retained in each group. With the outliers removed the effect of education was maintained. Inter-physician variation was reduced for LOS and average total charges following the educational reporting.
### Table 1. Result of sending physician-specific reporting to twenty physicians treating AMI.

#### 3.2. Pneumonia

On March 17, 1994, 34 physicians treating pneumonia were provided with the same reporting format. The first 134 patients treated after the reporting was provided (3-25-94 to 8-30-94) were profiled. The 139 patients treated just before the reporting was received by the physicians (1-1-94 to 3-17-94) were also profiled. The results are shown in Table 2. If this level of charge reduction was annualized for the estimated 483 cases treated per year at AAMC, the reduction of total charges would be $794,052.

Two and three outliers were again retained in the groups. With the outliers removed the effect of education on LOS was actually exaggerated with a reduction of 1.19 days in LOS. The removal of outliers had a moderate effect on the drop in average charges; $1,326 rather than $1,644. Effects on inter-physician variation were less pronounced with standard deviations for LOS and average total charges not reduced to the extent seen with the AMI patients.

### Table 2. Result of sending physician-specific reporting to 34 physicians treating pneumonia.

#### 3.3. Total Hip Replacement

The reporting process began with oral presentation of summary data for elective hip replacement and repair of femur fracture (with overhead transparencies) in the monthly department meeting of the Orthopaedics Service (OS) in December, 1992. During the first week of Feb, 1993 at the monthly OS meeting, more specific data were presented, including surgeon-specific data detailing consumption of hospital resources as measured by charges and LOS. Written summary documents containing surgeon specific-data were given to those surgeons present and sent to the two that were not present at the meeting.

Individual reports given or mailed to the surgeons identified them individually but retained confidentiality of the comparison surgeons. The educational activities encompassed a two-month period from Dec 1,1992 through Feb 3, 1993. This reporting scenario preceded that of AMI and pneumonia and varied slightly in format in that oral presentation was first made of the written data.
Table 3 presents the results for all elective hip replacements before and after the reporting period. Average total charges were adjusted for inflation and set to 1992 dollars. A seven percent inflation factor was used to correct for inflation based on a calculation provided by the hospital accounting department. At an estimated per-case reduction of $3,496, the 42 patients treated after the educational exposure generated $146,832 in overall charge reductions in ten and a half months. A comparison control group of patients treated by the same surgeons was constructed to validate the education effect.

<table>
<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
<th>Net Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOS (days)</td>
<td>13.75</td>
<td>9.93</td>
<td>3.82</td>
</tr>
<tr>
<td>Avg Total $</td>
<td>$22,103</td>
<td>$18,607</td>
<td>-$3,496</td>
</tr>
<tr>
<td># of patients</td>
<td>53</td>
<td>42</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Table 3. Result of sending physician-specific reporting to 7 surgeons performing elective total hip replacement.

A case-management (CM) protocol was implemented at AAMC for total hip replacement in late 1993 and the first patient entered the management pathway on 12-16-93. Surgeons performing total hip replacement were not provided additional surgeon-specific comparative reporting during the course of pathway development. The patients used for this post-reporting comparison did not participate in CM.

The actual aggregate reductions in average total charges for each of the three groups of patients profiled following educational reporting to physicians were $203,680 (AMI), $220,296 (pneumonia), and $146,832 (hip replacement). The total benefit for these three educational reports was $570,808. If the educational effects persist for a year in the physician groups, the annualized estimate of aggregate charge reductions for 390 AMI patients, 483 pneumonia patients, and 52 hip patients is $1,568,644. Cost savings to the hospital would be near $706,000.

4. Discussion

Many investigators have found there to be no severity basis for many variations in the consumption of hospital resources. Chassin, in 1987, concluded that differences in appropriateness cannot explain geographic variations in the use of expensive procedures, such as coronary angiography, carotid endarterectomy, and upper GI endoscopy [8]. Welch found a two-fold geographic variation in physician expenditures per admission and cited a lack of consensus among physicians about which services are required [9].

Physicians are interested in providing high quality care and in the present era of managed care and intense competition, they are becoming much more interested in making this care cost effective. Hospitals are equally interested in positioning themselves in an intensely competitive market by providing cost-effective care. Providing physicians with simple, easily assimilated data that profiles inter-physician variations in resource consumption can be effective in reducing variation and reducing mean measures of resource consumption.

Berwick points out that variations, such as differences in practice style that are not grounded in knowledge or reason, can be reduced without undermining the professional autonomy, dignity, or purpose of health care professionals [10]. Our physician-specific data is provided in a strictly confidential manner to physicians only and has not been made available to department chairs, hospital management, PROs, or third party payers.

Education-based physician practice reporting is an effective tool in encouraging more resource-efficient decision making on the part of medical staff members. Average LOS and total charges can be reduced significantly by providing physicians with profiles that show them their relative rankings with peers for several outcome and resource variables. Importantly, this can be done with a very low-cost low-tech computing system utilizing only moderate
technical skills and about three man-days per month. The benefits to institutions in competitive markets, third-party-payers, tax-payers, and patients do not need enumeration here.

Our process is non-proprietary and examples of the documents and details of our procedures are available to those with an academic interest or a desire to implement such reporting in their facilities.

5. References


Community Health Information Systems - 3
A Client Information System for a Community Oriented, Multi-Faceted, Pediatrics Health Care Centre

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Abstract

This paper will describe how a particular client information system is enabling process changes in a multi-faceted paediatric health care centre located in Victoria, British Columbia. The lessons learned are directly applicable to the re-structuring of the health system, with its’ emphases on bringing health closer to the home, and on the effective management of the health system in an evolving Regional environment.

The Queen Alexandra Centre for Children’s Health (QACCH) provides a broad range of multidisciplinary programs and services to children, families, and communities. Programs and services are available to infants, children, and adolescents with complex physical, intellectual, social, or emotional challenges, who require assessment, treatment, consultation, long-term follow-up, or coordination of services. Wherever possible, these are provided in the child and family’s own community.

In 1994, the QACCH embarked on an Information Systems planning process. The Information Systems plan recommended the implementation of a distributed client information system which would enable the many care professionals to maintain a comprehensive view of services performed for their client and his/her family. The chosen software solution, Eventscape, provides a central repository for diverse client-related information. By using object-oriented precepts, the software design is particularly suited to a rapidly changing environment.

We show how Eventscape is enabling process changes throughout QACCH and into its’ communities. We also describe how this client information system may support an evolving Regional System, and the lessons that have been learned in designing process changes that will accommodate Regional health program solutions.

Thanks: Thanks go to Mr. Mike Hendin of Eventwerx Software Inc. who are the developers and suppliers of Eventscape. Also thanks to Mr. Dennis Hulme of EDM Management Systems who was the project manager for the implementation of Phase One of the project.

1.0 Introduction

Across Canada the stirrings of health reform are being felt. For a number of years there has been concern expressed that the current institutional-centred notions of health care provision and, indeed, the notion that health is primarily determined by the quantity of health-care services available, have been under attack (see [1], for example).
The common themes of the newer approaches to health care services provision focus on:

- provision of appropriate services which improve health outcomes;
- the movement of services closer to home with greater consideration of the needs of the client;
- more effective and efficient management of the health system;
- increased emphasis on the continuum of care and where appropriate, integration of management and service delivery systems; and
- better evaluation of the affects of changes in the health system on the health of the population. [2]

Inherent in all these statements of intent, for the new world of health care service provision, are: client-focus, integration, community-orientation, efficiency, and evidence-based decision-making. These latter notions require coordination of services and events on an hitherto unprecedented scale. The new world of health care provision is information-intensive and decentralized. New information systems are critical to the implementation of an health system based on the marrying of decentralized care provision and the focus on the client as an integrated entity.

It should be remarked, in passing, that criticism related to the fragmentation and institutional focus of health care provision are not new [Florence Nightingale]. What has changed dramatically in recent years is our ability to implement economic systems that require large amounts of coordination at reasonable cost. This mirrors, and in many ways bypasses, the victory over the trade-off of quality and transaction costs that the quality movement has claimed in recent years. Indeed, it can be argued that the new health reform approaches would simply be too costly to implement without modern information systems.

2.0 The QACCH

2.1 QACCH’s mission

The Queen Alexandra Centre for Children’s Health (QACCH) is a multi-disciplinary, multi-faceted, community oriented paediatric Health Care centre located in Victoria, BC. The mission of the QACCH is to ensure that it functions and is perceived as a family centred, community-oriented, community based health service provider for special needs families and their children.

2.2 QACCH directional statements

Seven primary directional statements characterize QACCH’s vision as an organization. QACCH:
- is a healthy, flexible organization that supports and encourages staff
- adopts a family centred care model
- provides leadership in the development of coordinated, integrated paediatric services
- is a community-based and community responsive organization
- promotes common understanding of the organization’s role
- provides continuous quality improvement and strives to make a difference
- conducts research as a necessary component in the maintenance of standards of care and in the development of new approaches to the provision of services.

2.3 Programs, Services, Clinics

The role of QACCH is still evolving. Presently it is organized into four main service delivery streams: Finance and Operations, Mental Health Services, Children’s Rehab Services, and Family Services. The QACCH uses a program management model with functional departments, clinics, programs and contract services.

The services provided by the departments can be either clinical or support-oriented. Clinical services are those that are: stand-alone, available to any program, provided directly to clients or indirectly through programs or consultation arrangements, managed in the context of clinical standards where appropriate, and are based on a single discipline. Clinical services offered are: speech & language pathology, community integration, clinical psychology, occupational therapy, infant development, coordinated intake, pre-school education, neuro-psychology, physiotherapy, social work, orthotics, medicine, nutrition, nursing and seating. Support services consist of
development & community relations, continuous quality improvement, finance/material services, information services, volunteer services, research services, human resources, administrative services, admitting, health records, plant services, food services and education.

The programs are defined as: being significant is size and complexity requiring dedicated management, being multi-disciplinary, established for children with a common set of needs/characteristics, having specific admission and discharge guidelines, having protocols, and having specific evaluation standards. Existing programs include psychiatric response, psychiatric adolescents and children, psychiatric outpatients, residential discharge planning, rehabilitation respite, Anscomb House, under 3 and over 3 (Years of Age), Children's OP and OR.

The QACCH also operates a number of rehabilitation clinics to provide for children with specific needs/characteristics such as: swallowing disorders, visual impairment, seating, paediatric amputees, neuromuscular disorders, meningomyelocele, cleft lip palate, scoliosis and tourettes. Other services include the single discipline services, family resource services and services (some on contract) for school age children in the areas of school PT/OT, school speech, PDSP and private school where a number of clinical services are available as part of the program, service or on a consultation basis, and are further backed up by all the support services.

While QACCH continues to offer centre-based, inpatient care for its' clients, the emphasis is shifting toward an outpatient setting that is community-oriented and family-based.

2.4 Information System Goals & Objectives

The business goals and objectives of the QACCH mirror the major healthcare trends in BC. These are regionalization (albeit at the moment on hold), the movement towards promotion, prevention and community-based health, the adoption of the MIS Guidelines for reporting, and the focus on outcome and program evaluation. The implications of these drivers from an Information Systems standpoint are:

- the regionalization of the health care funding and service delivery will require a significant degree of coordination and communication among the community and with the funding agencies;
- there is an increasing demand to access client information from different locations by various partners, which require a highly flexible but secured information system that will allow remote access;
- the adoption of MIS Guidelines, the continuing focus on promotion, prevention and community health, as well as the focus on program evaluation will all require more detailed and a wider range of data to be collected.

2.5 Impact of Regionalization

At the time the Information Systems Plan was written regionalization of the health care system in BC was a major thrust. Of late this thrust has become somewhat blunted as the provincial government reassesses its' priorities and options. However, it would appear that some form of extra-institutional organization of the health care system is inevitable given the fiscal pressures and the desire to reduce duplication and provide a more effective and appropriate role to the provision of health care services. From an information standpoint the advent of inter-institutional coordination of care, the outreach programs to the community all point to integrated information networks between the various partners that see clients of the QACCH.

3.0 The Plan

The Information Systems Plan that evolved called for the implementation of some 44 information projects over a three year period. The total one-time and operating costs for the three years amounts to just 3.18% of the annual operating budget of QACCH.

3.1 Precursor

Historically, information systems for QACCH had been handled in a non-systematic manner, leading to a proliferation of disjointed systems. Information was duplicated across systems, leading to wasted effort as data was entered multiple times. In the absence of a corporate strategy for information systems a variety of software and hardware had been acquired. With respect to the management of information systems the traditional focus was on
the systems and technology aspects. A shift was required to the notion of managing information first and then concentrating on the supply of the technological tools.

### 3.2 Opportunities for Process Improvement

During the planning phase at least eight areas of opportunities for process improvement were identified. These process improvement opportunities formed the basis of the business imperative for the implementation of the information systems. The eight areas were:

- **Coordinated Intake/Client Registry Integration** - to move toward a centralized client registry to maintain all demographic and program/service related items on clients. This would integrate the more than 14 client information databases over five facilities that QACCH was formerly maintaining.
- **Program Evaluation** - this would extend the pilot project in mental health in terms of methodology and process for conducting program evaluation studies across the QACCH.
- **Client Profile/Care Plan** - the need for standard and individualized care plans (also referred to as intervention plans) and client profiles was cited by the medical staff, inpatient/outpatient mental health programs, nursing, nutrition and food services, under/over three program, school program, respite, discharge planning, social workers and volunteers.
- **Client Records** - an efficient client record system that can meet legal, accreditation and operational need, and release of information needs to be implemented. This has far reaching implications (e.g. the process for handling so-called “ghost” records).
- **Service Orders** - The ability to process on-line service orders such as material requisitions, housekeeping requests and room booking will improve the means of communication between staff members at QACCH.
- **Continuous Quality Improvement** - Presently, many CQI related activities are conducted manually. The computerization of some of the clinical and administrative functions will provide an opportunity to incorporate related CQI concepts into the newly automated process.
- **Parent-Held Records** - The parent-held record represents an entirely new concept of dealing with the client record where the patient is in control of his/her child’s record [4] - [7]. It requires a different approach to managing the client record and the information flow between the client and the staff.

### 3.3 Implementation Strategy

The Information Systems Plan for QACCH identified a total of 44 projects to meet the needs referred to above. To optimize the expenditures these projects were split into three streams: strategic - broad, cross-functional initiatives to support QACCH’s strategic directions, further a client-centred approach, increase QACCH’s competitiveness, and/or increase QACCH’s ability to respond quickly to external changes; operational - addressing more specific functional and information needs required to efficiently deliver the client and support services; and infrastructure - providing the foundation or back-bone upon which other systems and processes can be built. In particular, the following initiatives were identified as early priorities.

**Strategic:**
- Coordinated Intake / Client Registry;
- Program Evaluation.

**Operational:**
- Payroll and Accounting systems with MIS Guidelines reporting inclusive;
- Workload Management and Program Tracking systems

**Infrastructure:**
- Standardization of Office Automation tools, especially word processing;
- Establishment of Technical standards;
- Enhancements to the IS support structure;
- Establishment of a computer laboratory for user training.
3.4 EventScape and 1996/97 Strategies

It is clear that the implementation of the Information Systems Strategic Plan recommendations are having a significant impact on QACCH staff and practices. Not only are staff required to invest time to learn new systems, but they must assist in identifying the opportunities to improve business processes. As such the implementation has been strategically focused on the new Coordinated Intake/Client Information System.

During the preparation of the original ISSP it was determined that a fully functional Coordinated Intake/Client Information system was out of the financial reach of QACCH. However, in the first few months of implementation the EventScape software came available at an affordable price.

The decision to use EventScape enabled a number of the strategic goals to be accomplished with the one software base obviating the need to interface multiple systems. In recognition of this progress, the following strategies have been adopted for the balance of the plan period (i.e. to March 31, 1997):

- Focus on supporting QACCH’s core pediatric role;
- Organize and simplify the structure of the projects;
- Roll-out EventScape to all QACCH programs;
- prototype program evaluation activities;
- Evolve an information analysis capability;
- Advocate for a coordinated approach to common systems needs across the region;
- Improve the workload management system, in a regional context;
- Utilize regional Information Systems expertise wherever possible;
- Implement internal and external electronic communications;
- Standardize on one network environment;
- Adopt an evergreen desktop computer standard.

4.0 EventScape

EventScape allows a client-centred view of all clients and health services events. It is a client-server application built using Microsoft BackOffice server and Windows for Workgroups or Windows 95 as the client. EventScape adheres to such standards as SQL-92, ODBC and HL-7.

The software uses an object-oriented design approach whereby any health service event is modelled as an object. These objects can then be added to and modified over time and as health service events become more complex in regional settings.

5.0 Progress to Date

During the initial two years of the plan period (April 1, 1994 to March 30, 1996) the major thrust of IS activities has related to two fundamental aims: upgrade the technology infrastructure and implement a new Coordinated Intake/Client Information System - EventScape.

5.1 Infrastructure

Most offices are now linked to the internal Netware, computer network, all current workstations have been upgraded to the minimum standard of 486/33 running Windows 3.1. In addition a complete set of Office support tools has been implemented (based on MS Office) with the exception of internal e-mail. The external connections to community offices are based on modem connection and the use of PC-Anywhere for access to the Client Information System.
5.2 Coordinated Intake / Client Information

The advent of EventScape has enabled QACCH to concentrate the implementation on strategic information systems. Phase One of the Coordinated Intake/Client Registry project is now almost complete. Prior to the conversion of each department the operational processes were redefined. As each implementation is carried out the new operational processes are put into place. In Phase Two the external community partners will be utilizing the client registry in tandem with all QACCH programs. The implementation of EventScape also brought with it the benefits of management reporting.

5.3 Program Evaluation

A pilot program evaluation/research support project is underway to evaluate the results of the Mental Health Services. The Program/Service Resource directory is completed for internal programs. The external portion, taking into account non-QACCH services awaits a regional champion. Further, the advent of significant external communications awaits the provision of government-wide communications initiatives, such as HealthNet, at a reasonable cost.

6.0 Conclusions

Now that QACCH has passed the half-way point of their three year information systems plan there can be a reckoning of the lessons that have been wrought. These same lessons are of immediate interest to other organizations as they evolve networked systems beyond their own walls. Some significant points that should be borne in mind are:

Cost - in many health care organizations the advent of modern information systems is seen as a major cost. In many cases, as with QACCH, the existing technologies are old and idiosyncratic. To evolve rapidly to a modern, integrated system takes an investment outlook to information technologies. The rapid obsolescence of modern Information technologies is a major challenge. For instance, the 486/33 minimum technologies of two years ago was quite advanced. Today this is rapidly becoming old technology. EventScape technology is based on Windows NT technology, yet the prevailing network technology at QACCH is based on Novell Netware. Expenditures in this arena are not one-time, they must be fair and reasonable but continuing.

Process Changes - the degree of change that the roll-out of an integrated system, such as EventScape, would have on QACCH was not fully appreciated. This is particularly the case when partners and the community are involved widely. Along with the implementation of modern information systems must come rapid learning within and the constant ability and desire to eliminate old processes.

External Communications Means must be ubiquitous - to involve partners and the community widely there must be a means to communicate at low cost, and easily. The BC Ministry's HealthNet initiative has the potential of allowing all partners and communities to communicate via the internet. However, the initiative must overcome cost of entry barriers.

Project Simplification - in the burst of enthusiasm that QACCH went through in planning there was a wealth of immediate information systems needs that were identified. The scale of implementation of all these projects was not fully understood. Rather than attempting to launch on a plethora of projects a few clear priorities is a much more sustainable strategy. This is even more the case if the priorities can be focused on core businesses. In QACCH's case this is the paediatric role.

Common Approach across regions - it has become clear that integration of disparate systems across regions is difficult. A strategy whereby common systems are adopted for partners and communities and where regional IS expertise is utilized rather than each organization trying to go it alone is the only sustainable approach.
7.0 References


[5] Queen Alexandra Centre for Children’s Health Information Systems Plan


The Community Equity Model of Health Care: Framework, Theory, Technology, and Data

David E. Ford and Leslie Pentland, Ph. D.

Abstract: Today’s increased trend toward large scale government or corporate organization of health services may jeopardize client service responsiveness and may not achieve reduced cost objectives. The authors combined senior operating experience in health care financing, suggests that health care delivery reform can best be achieved by facilitating community operating units which excel in service and achievable health outcomes. These community units, referred to as a Community Equity Model, are self governing, accountable to the client users rather than national governments or economic corporations. The authors believe the technical and organizational constraints preventing this type of organization are rapidly disappearing and suggest several theoretical frameworks, information requirements and areas for further research for broad implementation of this model. They suggest economies of scale and scope strived for by ‘vertically integrated systems’ would be achieved by new transaction infrastructure companies.

Key words: Networks, Community-Based, Health Care, Community Equity, Information Technology, Sociotech Systems Theory (STS).

Introduction

In the last generation of organizational design, throughout the first three quarters of this century, large scale and standardization caught our imagination and energy. The result is we built corporate institutions, whether government service or economic organizations, of huge size which were generally centrally organized. These giants of organization and how to run them; how to make them productive; how to survive in them as a member or as a user, have become one of this late century’s greatest paradoxes (Handy, 1994) and one of contemporary business and policy leaders greatest dialogs (Naisbitt, 1994).

Historically the industry of health care has had mixed impact by this organizational phenomena. In Northern Europe, the former Soviet Union, Canada and Australia large scale government as a single payer has created extremely central policy and administration toward the medical service system, if not the actual ownership of the medical practices or hospitals.

In the United States, most recent trends are increasing toward national for-profit corporate ownership of hospitals and physicians. Profit and not-for-profit hospitals (even non-profit health insurance entities) are being consolidated into national systems such as Columbia/HCA. Physician practices are being purchased and doctors becoming salaried employees by selling their practices into what are now referred to as Physician Practice Management Companies (PPMC’s) such as PhyCor or Medical Partners, or purchased by their local hospital system to create Integrated Delivery Systems (IDS), a term written about and popularized by academic faculty in health care administration graduate schools (Conrad & Dowling, 1990). This trend toward corporate medicine in the United States was well prophesied in (Fuchs, 1974) and (Starr, 1982). Capra, as well, anticipated the transition from a service industry to a business system in 1982:

The aim of the health industry has been to turn health care into a commodity that can be sold to consumers according to the rules of the "free market" economy. The "health care delivery" system has been structured and organized like the large manufacturing industries using the mechanistic model.

The current system favors a highly centralized and technology-intensive approach that is profitable for the industry but expensive and unhealthy for the patients (Capra, F.).
CRITICAL QUESTIONS

The fundamental question about large scale and centralization in medical service is whether the old convention, "Bigger is Better" (particularly in a human service industry such as medicine) is truly operative any more. We have seen in manufacturing production that smaller and leaner is often more adaptive and customer oriented, and even lower cost. With the demand for local fit and variation, are large centralized systems inherently unmanageable and unadaptable in the future?

In the US, in addition the threats to the rural health infrastructure (Amundson, 1993), one of the very real but poorly articulated concerns with this massive conversion of non-profit hospitals and proprietary medical practices into private and public corporations, is that the equity exchange is occurring at a level, in many instances, that is unsustainable from the basis of existing revenues, let alone the reality of future diminishing revenue. As you can see from Figure 1 the capitated rate trend in maturing US markets is dropping from $125 US per member per month to less than $100 US.

![Total HMO Cost Trends](image)

An example of this for-profit conversion is Caremark's purchase of Friendly Hills, a 150 physician medical system in southern California. The price per physician was $1,727,667 (PPMC, July, 1995). Although it is acknowledged that acquisition and consolidation occur before integration and traditional economies of scale, there are real questions whether the nature of the industry can support these high acquisition costs in addition to financing the capital necessary to restructure the existing infrastructure required to reduce long run operating expenses. If they do not, then serious and permanent damage to the community health delivery structure may result.

Our learning and observation of corporations over the last 25 years is that there is often an inverse relationship between size and centralization and organizational survival, service and vitality. The natural questions are should national health care systems remain national or should they systematically 'decompose' into local self governing entities with national orchestration for support? And should local community systems in the US roll up into national corporate systems or should they find an organic way to configure so they will not have to sell out to remain a player? If they were to do so, is there a credible model for such a transition?

The Community Equity Model

We think so. These are smaller, very integrated delivery systems that do not require equity purchase, but work on the basis of collaboration and contractual agreement among participants rather than ownership. We call this alternative a Community Equity Model (Ford, Kissick, 1995). Here 'equity' is used in a different sense of the word than 'cash value'. Equity, in this sense, is viewed as equality of community members, community ownership and direction, justice as in the king's court of equity.
'Community' here is meant to be people who have a connected sense of belonging together because of common interests or beliefs. Usually this is in a geographical region such as a defined town or city. We have also used the concept within cities as a neighborhood health plan. Sometimes the 'community' is a connection based on ethnicity or religion. For instance, in the Seattle, Washington area we have several community plans in the international district which serve Vietnamese and other Asian populations.

A new organizational structure which mediates among the parties of interest is needed to meet the requirements cost efficient and care outcomes of the future. The "Community Equity Model" organizes care at the local neighborhood or community level using the community as the actual funds holder. This puts the critical stakeholders in a practical mutual ownership relationship by making allocation, services, and resource accountability a local act.

The model offers communities of providers and consumers a way to organize a community health plan and the supporting infrastructure technology that creates all the managed care requirements to compete in the short and long run with centralized models without having to "sell out" to big systems. It builds upon the natural geography, ethnicity, or organizational affinity groups to which people (both consumers and providers) already have a sense of belonging.

The key is for a local entity to become the funds (premium) holder and govern the distribution for those funds locally in a system which actually accountably meets the needs of the community for which it is meant to buy services. Figure 2 below illustrates the consolidating function of payment in a US environment.

**Community Health System**

![Diagram of Community Health System]

The model, 1) creates a manageable structure organizing services from the center outward, 2) distributes financial risk for services by "layering" them and apportioning that risk out to those parties best able to manage the risk, and 3) uses internal risk and quality assurance techniques to assure tight performance by the managed care system. The objective is to design and implement a system of care and management that is inherently manageable.

The objective of this model is to create a sustainable healthcare management structure to receive medical funds and mediate supply, demand, services and outcomes at the local level. This funds holder structure is a voluntary one in the sense that it is not a subsidiary entity created by state or federal government. Its charter, governance and leadership comes from the user power of consumers and providers, not state authority. State authority flows through contracting to pay this entity for services and with that authority can flow accountability and standards (hopefully for outcomes not processes).
Fundamental to the Community Equity Model is in the placing of the purchasing power of the health care system for the population of a community in the hands of the community leadership itself. This allows the community to organize the delivery service network from the primary center outward to the acute and tertiary sites. This has a profound effect on the future structural relations among the parties, namely it means the specialists will work in a more supportive relationship to the primary system rather than autonomously doing their work. In cases where the specialists receive a subcapitation, the working relationship is very collegial and mutually supportive relationship.

Integration of the delivery system begins with the primary care providers (Figure 3). The community network first works through a coordinated system of services within its primary system, then contracts for care upstream with acute and specialty providers partners. We have used this approach within large urban communities 2,000,000 people to organize.

- IntraUrban
- Ethnic clusters of primary providers,
- Rural Communities, and are
- Are exploring work within Intra - Organizational units of Providers within larger vertical integrated system.

**Primary Centered Vertical Integration**

Components of an Advanced Delivery System

The Community Equity model of organizing managed care presents an organizational structure for local integration and horizontal integration and linkage as an alternative to a centralized, hospital or insurance company vertically integrated model. Although there similar objectives with traditional vertically integrated models, i.e. to compete on the basis of price, service and quality, the manner of accomplishing these objectives is significantly different in ways we believe are qualitatively superior in the long run for patient and provider satisfaction in a knowledge base service such as medicine. The model fundamentally shifts the locus of power, decisions, and epi-center for a clinical care organization from the centralized professional organization to the local community, in the broad sense of community.

This decentralized model encourages the building of networks; at its heart is the collaboration of all parties in working toward a common goal. Health care is communication; it is the sharing of information; it is the partnership of the patient, family and provider. Health care is inherently local; it is the caring relationship of the patient and family with their providers, building on the foundation of primary care. At its heart is the collaboration of all parties in working toward a common goal. This model encourages self-sustaining, self-correcting and self-learning organizations and individuals.

The difference in this approach to organizing and managing the delivery system at the local level has to do with a fundamentally different operational approach to organizational effectiveness that the traditional economic
‘production’ approach articulated by such researchers as Doug Conrad and Stephen Shortell (Conrad & Shortell, 1996).

We believe that the articulated model can be further enhanced using two theoretical frameworks developed from business and information sciences, namely Sociotech Systems Theory (STS) and Organizational Network Theory. Our observation is that the natural evolution of local provider systems into management and governance units of local scale which have not been acquired by larger systems are developing along these lines because they naturally align scale, technology, and the structures to adapt to the more rigorous demands of tighter integration.

Since the authors are operators, not organizational researchers, we offer the analysis below with some hope that more academic researchers can develop the concepts.

**Theoretical basis for Community Based Health Programs Ground in a) Sociotech Systems Theory (STS) and b) Organizational Network Theory**

Dr. Pentland's dissertation research and area of specialization used as a theoretical basis the sociotech systems (STS) theory, model and approach. The traditional STS model includes three entities: people, technology and organization in two relationship systems: the social system (including people and organization) and the technological system (including technology and organization).

![Diagram](image)

Work on the social side includes "feel good for awhile" interventions such as personal career development, stress reduction, problem-solving, team building and group process. Today there is lot of work being done on the technological side. This work includes organizational restructuring, job redesign, industrial engineering, business process redesign and re-engineering.

Peter Senge has suggested that systems thinking is a discipline for seeing wholes, for looking at interrelationships rather than linear cause-effect chains; he sees us entering the Age of Interdependence. Senge focuses on the individual and the organization all but neglecting the effect of today's technology on either (Senge, 1990). Senge works with the social side. His colleague Michael Hammer suggests that we should obliterate existing systems and re-engineer the organization with today's technology. Hammer and Champy focus on teams within organization, not on people as individuals. They re-engineer with technology (Hammer & Champy, 1990). Clearly, they work on the technological side.

The term sociotechnical systems reflects the goal of integrating and optimizing the social requirements with the technical requirements for the benefit of the organization. Eric Trist was the leader of the STS approach and a founder of London's Tavistock Institute of Human Relations. Although it's roots are in manufacturing, STS redesign is now being applied to more varied, non-manufacturing environments.

A major premise of STS is that these subsystems must be considered interdependently because arrangements that are optimal for one may not be optimal for the other and tradeoffs are often required. Thus the need for dual focus and
joint optimization (Fox, 1995, p. 92). The principle of joint optimization refers to the idea that the systems must support and reinforce each other (Emery & Trist, 1973; Trist & Bamforth, 1951; Trist, 1981).

The STS approach is based on open systems theory and considers the environment in which an organization exists. Certainly today’s environment with its chaos and complexity must be considered in any organizational design. And we know this is particularly true in health care.

Cal Pava of the Harvard Business School introduced important additions to STS theory and methods. He expanded the applicability beyond its roots, beyond the well-defined linear systems. For complex, nonlinear situations Pava showed how organizational changes can lead to more productive results. The goal, as he stated it, was to use STS to organize people, work, and tools efficiently and effectively. He established the presence of positive feedback loops within the subsystems (Pava, 1983). In 1994 Deon Zell of the University of California, Los Angeles showed how STS redesign can bring about system-wide change, how it can produce changes in individuals’ belief and behaviors.

Leslie Pentland recently conducted research specific to the relationship of people and technology, establishing the presence of the 3rd systems relationship, the 3rd side of the STS model: the systemic relationship between people and technology. Her research also suggested that technology enables humanness in organizations enabling many adults to move towards higher levels of self-actualization and personal mastery because of the enhancement of personal capability and effectiveness created by technology and organizational support (Pentland, 1996).

The traditional context or unit of study for STS work has been the business organization. It occurred to us as we took another look at community-based health care concepts that it might be interesting to do so using the framework of the STS theorists and practitioners. The context or scope of observation would change from organization to community. The social system in this case health care and the technical enabling systems computer and communication-based networks. The people include patients, providers and other community leaders.
We are calling for a systemic approach, a whole systems point of view to today’s complex health care design needs. We understand that the social and technical systems aspects are only part of the picture of community-based health care. Also important are the economic and financial aspects as well as politics and governance particularly, the human relationships: the one between people and community, between people and technology and between patient and provider. We feel the STS model is particularly appropriate, especially with the development of the concepts by Pentland, for explaining the sustainable dynamics of a human service system such as medical delivery.

A second body of knowledge, literature, theory and models that we draw on is Network Theory especially network organizations and the role of today’s technology in enabling this emerging structure. As the old centralized, hierarchical models of organization are breaking down, dissipating back into core elements, core competencies, these elements will reorganize into new, more complex molecular-like structure. Today’s technology literally connects the elements, seemingly invisibly: anytime, anyplace. Today’s technology enables the emerging network structure of organization.

Linda Harasim, editor of the book Global Networks: Computers and International Communication observes, Historically the introduction of new communication tools has transformed humanity. The use of computers for communication will further enhance and expand how humans connect, communicate and create community. Today’s networks enable communication of active participants, enables the extension of human community onto a scale that is unprecedented (1993, p. 1).

Johanson and Swigart describe the emerging organizational model as a fishnet: a flexible structure of temporary ad hoc hierarchies, cooperative alliances and horizontal flows from supplier (provider) to customer (patient). They declare that information technologies are the cord out of which the organizational fishnet is woven (1994, p. 18).

This structure redefines traditional boundaries. It requires more cooperation between competitors (payers), providers and patients making it harder to determine where one entity ends and another begins. This structure makes the participants far more reliant on each other and requires far more trust than before. As McLagen and Nel report, "When work is carried out through networks, an organization’s structure changes whether you want it to or not" (1995, p. 128).

Today’s Health Care Delivery Models

We see in place today a variety of organizational structures providing health care delivery services. The Canadian model is a single-payer structure with centralized authority and control. Viewed as one point on a continuum this form represents the old hierarchical, bureaucratic structure. On the other end of the continuum we find the "Internet model," a more temporal, virtual style of organization. The predominant structure in the United States, like the
Internet, is a collection of provider-driven delivery systems owned by many different corporations each providing centralized authority within their own systems but not for the system as a whole.

The community-based model that we are discussing today is a hybrid organization, somewhere towards the middle of the continuum. We believe that it is a more optimum way of managing health care and improving the health of the community.

Technically the system is a network of community networks each connecting up but only as needed. The community-based model mirrors the concept described in much of today's literature on globalization where cities, communities, become more like business organizations working in collaboration and participation with local entities as well as with outside entities; functioning both as a local system and as a global player (Kantor, 1995; Sassen, 1996; Porter, 1993). It is local community networking and federation management in combination.

This type of health care system requires organizational change and is enabled by today's information technology. It relies on the use of computers and communication technology to enable the decentralization of information and communication to the point of service, where the information is needed and to the knowledge workers who use it. This requires that management let go of the control of information -- that they share the power of information.

**Enabling Information Technologies**

The challenges facing managed care organizations are formidable. Health insurers realize that they are no longer in the claims administration business; they are in the business of delivering health care services. Information Technology can help the industry meet these challenges.

Today's Information Technology includes database and ad hoc reporting, data analysis and modeling programs, administrative support and record-keeping capabilities as well as data communications to support application and enrollment transmission, premium billing and eligibility checking.

An extensive communication network capability will be required to connect, link together the entities within the system -- the providers, the plans, the employers, and, in the case of the senior population, government workers and government. These connections will enable the organizations to communicate with each other and exchange information in a highly secure timely manner. Collaborative community activities to develop and implement standards must continue.

Emerging in the market place are information network systems referred to as Community Health Information Networks (CHINs). Geographically separated hospitals, clinics, laboratories, pharmacies, primary care and specialist physicians can all be linked into a single, confidential communication system, a series of networks within networks. This technology enables the networking of entities within the health care system in a seamless way and helps them to function as a whole interactive system. This linkage is an important part of the underlying infrastructure for managed care.

Another important part of the underlying technical infrastructure is an information repository -- available for ad hoc use and capable of serving the integrated reporting needs of financial, clinical, and performance data with patient information. These databases need to provide data on quality, service, and performance of the system as a whole.

And finally the process-management system itself which needs to keep track of eligibility and utilization, pay providers the scheduled amounts, track referrals and so on. The challenge here is material because the new system will require individual-based record keeping rather than the traditional group-based record keeping -- a major infrastructure change.
Information Technology Implementation Experience – The Alaska Community Health Information Network.

The Implementation Strategy was straightforward:

We will add value to the provider and, consequently to our provider relationships, by "enabling" the provider desktop with software and connectivity that will help automate the patient medical record, provide electronic messaging such as referrals and test results as well as provide electronic messaging between providers, payers and government. We will also provide data back to the providers for self management and reporting to the government (BCWA, 1994).

In Alaska the strategy was to establish the network as THE state network for an electronic claims clearinghouse function, a data warehouse and the provider communications link for the State of Alaska. The marketing emphasis was the community, "linking entities within communities and communities within the state and the state to other states within the region."

The tactical plan was to identify key physicians or physician groups, install them and then identify and install their five most frequent referral entities (e.g. other providers, labs). We planned to implement hospitals concurrently with the provider groups. Operationally we were prepared to literally give the software and hardware away until we reached critical mass. At that point we felt the "rest should follow." We had a technical support team on site for installation and on hand for the first 30 days. There was a 7d/24h help line for phone calls.

The network in Alaska is an open network, open to any entity within the health care delivery community who wants to participate. It is being sold as a community-based communications network connecting entities within a community, one community to many communities and the many communities to the region. The package includes PC hardware, communication hardware and software and value-added desktop software; it is menu-driven, user-friendly, point and click, with color graphics.

Note: The network in Washington was rolled out initially as a proprietary network built and used for proprietary gain within a closed provider network. It did not even begin to become a viable network on this basis be a tool for community-based advantage. The illustration above is to demonstrate the availability of technology and application for this kind of effort.

Implementation Results: What Went Well

(1) Design and Prototyping Development. We conducted extensive technical and management investigation into the base products. We built and tested a prototype. We made sure that we had a high quality, user friendly "look and feel" and a sound technical architecture and design documents.

(2) Implementation Planning. Marketing was planned by an integrated team. Outside marketing specialists who had done this kind of work before were hired on an outsourced basis.

(3) A Phased Approach. We began with two pilot or demonstration sites being sure to select those providers who already demonstrated success with systems and who seemed eager to use the new network. Phase 2 was to build critical mass by connecting based on referral patterns for our initial sites so that they would have effective utilization. We felt that the third phase would be an almost, "by demand" phase with community peer pressure to get on board. The plan was segmented by geographic location. Separate marketing teams were devoted to those areas, goals and results.

(4) Steering and Management Teams. A multi-disciplinary steering committee was put in place. Regularly scheduled meetings were held to assure that decisions were made on a timely basis. A core management team representing the different disciplines and companies was assembled and likewise meet regularly to assure that problems were brought forward and resolved on a timely basis. A joint marketing and technical installation team was put in place to coordinate needed activities at that level. Technical work groups were formed as needed for specific problem resolution.
(5) **Participatory Team Approach.** There were important relationships that needed to be managed at all levels between each of entities. We experienced good inter-disciplinary and good intra-company teamwork.

(6) **Technology to the Desktop.** The marketing team was incentivized to get the technology on the desktop, up and ready for activity. They met this goal with great success. However, they were NOT incentivized to get business volume through the system. A major flaw in planning and implementation design.

**Implementation Problems**

(1) **Community Building.** The marketing material emphasized the community and communications of the system but there was little supporting action to go along with the words. We talked about adding value at the desktop, in the office, but we did nothing to assure that the people at the desktop, the end users saw the added value. The system exchanged business transactions but it did not build community between the entities.

(2) **Work Patterns.** The system did not change people's work patterns because it did not change the work flow at the desktop. Consequently people installed the system but did not put much work through it. They were continuing to do business in the same old way. We did NOT look at this from an organizational change perspective and this was a critical mistake.

(3) **Desktop Representation in Core Teams.** We did not include anyone from the provider desktop in our core teams. We had left that up to the software vendor to handle through routine user-group teams. They did not adequately handle the larger, more strategic communications, community building pieces.

(4) **Dedicated technical staff.** Initially the only fully dedicated staff was the marketing team. Timing and getting people together was often an issue. This was further aggravated by their geographic distance between several of the players.

**A Second Example of Building Community -- The TAOS Experience -- a Community Information Network, where health care is only a part, but an important part, of the information network**

The LaPlaza TeleCommunity is a community network intended to provide people in the community new ways to come together in a spirit of well being, enterprise, concern, and leadership. Through partnerships across the private, public, educational, and governmental sectors the network is being built one town at a time by individuals who see the vast potential. The goal is to provide democratic access to information and communication resources for rural communities in New Mexico. The network includes federal, state and local government; business; education; health care; libraries; and the community at large.

It is a member-supported, public-interest, on-line computer network that gathers and disseminates multi-sector information. It provides a vehicle for citizens to gain access to local, national, and international computer network resources.

The Taos Valley is rich in cultural diversity and provides an ideal environment to test new technologies. Native Americans, Hispanics, and Anglos have lived here for generations creating a diverse population in a rural and remote environment. The objectives of an interactive community network include bringing people together in new ways, opportunities which do not sacrifice cultural identity, promotion of community self-reliance and access to new national and international resources.

**Summary**

The requirements for service, efficiency, and accountability in health care financing and delivery in developed countries will take on new forms in the next century. In part, these forms will be shaped by policy and economy. In part, they will be shaped by available technology and new organizational capability for more intimate scale created by that technology.

The authors believe that somewhere between “Big is Best’ to ‘Small is Beautiful’ there are a human scaled organizational structures that are inherently manageable and accountable for health care services. The authors,
through there practical experience in health care system design and information technology background, suggest that
the scale is, broadly speaking, a ‘community scale’ and suggest a fundholding and management model called a
‘Community Equity Model’ as an example of reorganizing care financing and delivery at the local level.

Out of our reading and lived experience of organizational changes, we suggest several theoretical frameworks, i.e.
sociotechnical systems (STS) and organizational network theory, to complement traditional pure economic
explanations for these changes. We would call on scholars and policy makers with other experience bases to further
articulate, research and develop working frameworks for health care integration besides big, centralized models for
this coming century.

These new models must serve all of the constituents within each system of care – physicians, administrators and
consumers. They must manage data in a responsible way, gather it, secure it, provide access for analysis on a timely
basis to those who need the data.

And finally the infrastructure must have an evolving architecture, serving local needs while providing a regional and
national reach. The design and implementation requires thoughtful strategic alignment of technology with business
need. And there must be a mechanism for ongoing change, for growth and evolution.

We would also suggest that there will be a significant new industry developed to serve the health care industry
which would be health infrastructure companies specializing in network management, information connectivity, and
information services. It is these new knowledge based intermediaries which will create the economies of scope and
scale prior vertically integrate manufacturing firms created for the products industries.

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Dealing with Information Accessibility and Security

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Keywords: Security, Confidentiality, Information Access

1. Introduction

Security control used to be relatively straightforward to implement. With limited-function workstations physically attached to a particular processor, end users could be relegated to specific applications, and, in most cases, prevented from accessing unauthorized data through application-based security alone.

Today, this is no longer the case. Workstations are more powerful and are typically attached to a network (either direct or remotely), on which various applications reside, making end users only a password away from a wide variety of information sources.

Complicating matters even further is health care reform. Hospital consolidations and the move to delivery systems are fueling the requirement for making standardized accurate data available for clinical decision making and comparative analysis, while ensuring that confidentiality and security are not breached.

Providing appropriate access to information while ensuring that it is protected from unauthorized intrusion is not an easy mandate. It requires more than the security methodologies utilized to date.

Enterprise Wide Security
2. Methodology

The issues that must be considered fall into three general categories: a) administrative issues, including proper password procedures, day-to-day monitoring, periodic audits, back-up procedures and other such security processes; b) authorization issues, including user IDs and identity verification; and c) application control issues, including user-specific application usage and application access audit trails.

Probably, the most difficult issue to address is that of authorization. A system can only be secure if it is known who is accessing it. Passwords act as the first line of defense. But equally important is ensuring the individual entering the password is actually who he or she claims to be.

One of the more recently developed technologies that addresses the authorization issue is that of "Single Sign-on," which takes the responsibility for managing security such that end users enter a single sign-on and password and are presented with a workplace that shows only the applications they are authorized to access. Individual sessions are controlled by a security broker each time a session is opened or closed, eliminating the need for end users to memorize individual passwords by application. All significant end user activity is also logged so as to allow for analysis.

Single Sign-on Products Free End Users From The Responsibility For Managing Multiple Passwords

Because end users have no knowledge of how to access applications directly, they cannot share with others, either intentionally or inadvertently by virtue of having written them down, password access. Given that it is not uncommon for end users in complex environments to actually have ten to thirty different passwords to various systems, Single Sign-on technology also resolves a procedural issue as well.

There are several commercial implementations of Single Sign-on technology, the most powerful of which include three components: access control, whereby the system takes responsibility for presenting only authorized applications to individual end users and managing passwords to the various applications, as well as automatically updating application passwords when they expire; authentication, which ensures that transactions are initiated only by authorized end users; and time-stamped encryption of all network traffic, which ensures that information is not intercepted or otherwise compromised.
More Advanced Single Sign-on Products Also Deal With Authentication And Encryption

Two industry standards have evolved that also should be considered when implementing a Single Sign-on solution - DES for encryption (transforming data into a form unreadable by anyone without a secret decryption key) and Kerberos for authentication (a methodology for ensuring the identity of the sender and the integrity of the message).

An adjunct area of security control which is quickly gaining acceptance is Application Control, by which a new layer of security is introduced between the end users and the applications they use, transparently to the applications. Application Control limits end users' use of applications in such a way that only particular screens are visible, only user-specific records can be requested, and all uses of the applications can be recorded for audit purposes. Application Control is done transparently to the applications so no changes need to be made to the applications involved.

Application Control Controls End Users' Movements and Keeps an Audit Trail of Significant Events

The integration server prevents end user access of unauthorized patient records, recording attempts to access unauthorized information, transparently to the Patient Care application.
In its simplest form, Application Control technology can transparently monitor existing end user interactions with applications and prevent end users from traveling into parts of an application or input data that they are not authorized to do. For example, Application Control can prevent a clinician from accessing subsets of the patient population, transparently to the patient care application.

In a more advanced form, Application Control technology can be used to add options to existing end user screens and use those options to navigate to other systems' information. For example, a new option can be added to an existing Patient Care menu screen so that nurses can seamlessly access LAB results for only specific patients.

**Application Control Uses Automated Navigation and Copy/paste to Transport End Users to Information**

![Diagram showing automated navigation and copy/paste]

In its most advanced form, Application Control technology can be used to build simplified consolidated views for personnel that need access to a number of information sources or for allowing business associates to gain computer access to various information sources. For example, a consolidated view of patient information can be developed for physicians and nurses that need access to a number of departmental information sources, all without modifying any of the existing systems.

**Application Control Determines What Information is Presented to Users Through the Use of New Views**

![Diagram showing entirely new presentation]

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167
Despite the new environments under which healthcare institutions now run, proper security is achievable. The combination of comprehensive Authorization and Application Controls can provide a secure distributed computing environment without sacrificing end user productivity requirements.
Heart Health Information System: A Tool for Project Management

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Abstract

The Heart Health Information System (HHIS) was developed to manage and measure community health initiatives of the British Columbia Heart Health Demonstration Project (BCHHDP). The purpose of the HHIS is to capture data in a timely and effective manner for use in operational planning, the production of reports, and for the dissemination of successful project components.

The information system allows for the input of data from Operational Plans, Quarterly Reports, Meeting Minutes and Community Specific Evaluations. It is also designed to produce reports based on these data sources both quarterly and annually.

The information relating to operational planning is used by all levels of the project from the community coalitions and coordinators to the principal investigators. The information is used developing operational plans which address implementation of initiatives, budgeting and resource allocation; and identification of process, impact and outcome indicators.

The reports produced by the HHIS are used by the central management team assessing the status of the community initiatives, determining how best to provide technical support to the communities and responding to reporting requests of the project funders (NHRDP and BC Ministry of Health) and community stakeholders.

The information produced by the HHIS will be invaluable in determining costs (resources), health impacts and outcomes (results), reach and public support for the initiatives carried out by the community sites. The ability to relate health outcomes to service cost and utilization is important for program performance evaluation and utilization management.

1.0 Background

The British Columbia Heart Health Demonstration Project (BCHHDP) is a five year research demonstration project jointly funded by Health Canada and the British Columbia Ministry of Health. The BCHHDP is a comprehensive community-based multi-risk factoral program designed to reduce cardiovascular disease risk factors and ultimately cardiovascular disease in the four demonstration communities - Squamish, North Shore, Upper Island, and Cranbrook/Kimberley. Each of these communities carries out its own community assessment, program planning, budgeting and implementing of activities or initiatives and reports back centrally.
One of the recognized needs of the BCHHDP has been to provide central technical support for the communities. The Skills Assessment Survey (spring 1994), the operational planning process, monthly conference calls and quarterly Provincial meetings have guided the provision of technical assistance by the Provincial Coordinator and the Central Team (consisting of the Provincial Coordinator, the Database Administrator, and students) to the communities and the Coalition. The need for technical assistance, reporting to the funding agencies, and management of data collected on the seven goals of the research project across a variety of sites and methods resulted in the design, testing and use of a heart health information system.

The Heart Health Information System (HHIS) was developed as an automated record keeping system to support project management, accountability and operations of the British Columbia Heart Health Demonstration Project (BCHHDP). A primary purpose of the HHIS is the efficient recording, transmission and analysis of information for operational and strategic decisions. The system tracks data in a timely and effective manner for project management, operational planning, decision-making, reporting, assessing progress, monitoring expenditures, contributions, and diffusion and for the identification of successful components of the project for dissemination. The HHIS is specifically designed for the management and evaluation of community health initiatives (inputs, throughputs and outputs).

In addition to providing a mechanism for tracking the progress of planned activities HHIS provides a means of evaluating the effectiveness of the interventions themselves. Data is collected and analyzed at the individual, organizational and environmental level through surveys, participant and event tracking forms, as well as quarterly and annual reports.

2.0 Methodology

2.1 Development

The HHIS was developed in conjunction with the Evaluation team activities of the BCHHDP. A needs assessment was conducted with this team and Demonstration communities based upon the seven goals of the BCHHDP, reporting requirements of the funding agencies, the strategic directions of the project and the multiple method, multi-site approach to data collection. The Database Administrator and the Provincial Coordinator travelled to the communities and the BC Heart Health Coalition to interview these end users to determine how the system could be responsive to local project management needs. One of the seven goals of the BCHHDP is participatory evaluation. This form of evaluation requires ongoing feedback to, and validation of data with project stakeholders. Data is used for planning and decision-making on an ongoing basis. Interviews were based upon the uses of the data at all levels. Therefore, the system has been developed to meet evaluation requirements, operational and strategic planning needs and as well as the reporting requirements of both the British Columbia Ministry of Health and Health Canada.

2.2 Description

This information system runs on Microsoft Access, a relational database system for Windows. The information system is accessed through a series of selection screens. The user can choose to enter data, produce reports or continue development of the database. User friendly screens will lead the user to the forms needed to enter data from operational plans, quarterly reports, meeting minutes, activity tracking forms, and presentations (see Figure 1). The forms are easily filled in as many of the fields are either pre-formatted or in the format of a selection list.

The HHIS has a number of reports set up to run either quarterly (after entering data from the Quarterly Reports) or annually (see Figure 2). These are reports based on information provided by the Community Coordinators in the Quarterly Reports. These reports are designed to meet reporting needs for Ministry of Health and Health Canada, as well as the need within the communities for project management.
2.3 Data Entry

The following types of data are entered into the HHIS either on an ongoing basis, or quarterly. The BCHHDP utilizes a multi-method evaluation approach and therefore the system allows for the input of both qualitative and quantitative data. With the exception of monetary values and contributed hours quantitative data is either nominal or ordinal. To date the input is primarily qualitative.

Fig 1. Example of a data entry form from HHIS

Fig 2. Example of a report format for Quarterly Reports
Meeting Minutes:

The date, attendees and association, committee description, agenda items, actions and meeting length where provided are entered into the HHIS for all Community, Provincial, Coalition, and Evaluation Team meetings. Meeting minute actions are entered verbatim into the HHIS while the agenda items are summarized. Where the actions are unclear the database administrator adds details from the agenda items discussion to elaborate the issue.

One of the limitations of the meeting minutes data is that the entries are dependent upon the accuracy of the individual taking the minutes during a meeting. No training in minute taking or minute format has been provided. However, it has been noted that the minutes have become much more concise over the course of the project. In addition, where the actions have been elaborated the data is subject to the database administrator's interpretation. However, all the data has been entered by the same individual.

Quarterly Reports:

The Community and Provincial Coordinators submit a structured Quarterly Report at the end of a three month period. In some circumstances the Chair of a specific initiative committee at the community level contributes to the information provided. Each initiative is reported upon separately. The data for the initiatives includes highlights and lessons learned, influencing factors, outcomes, internal tools, products, publicity, diffusion, sustainability, timelines, in-kind contributions, financial statements and administration. The appendices of the Quarterly Report include copies of any internal tools, products or publicity.

Most responses are written by the Coordinator and are therefore limited to their perspective. The notable exception is the Provincial Quarterly Report which includes input from the Principal Investigator and the Database Administrator as well as the Provincial Coordinator.

Activity Tracking:

The activities of the Principal Investigator, the Provincial Coordinator, the Coalition Chair and the Coalition Secretariat are tracked either on a weekly basis in the case of the Provincial Coordinator or on a monthly basis for the others. This data is collected by either the Database Administrator or a member of the Evaluation Team interviewing the individual. The interviews follow a structured format. Key contacts, key issues for each stakeholder, time spent on initiatives, meetings, influencing factors and in the case of the Coalition Chair questions relating to activities which will affect sustainability of the project, are asked. This data is entered verbatim.

This data is limited by the ability of the individuals to track and remember the activities in which they have been involved over the interview time period.

Operational Plans:

The Communities, the Evaluation Team, the Coalition and the Central Team all submit annual operational plans. The data from these plans is entered into the HHIS on an annual basis. The operational plans are developed for each initiative and include objectives, indicators, strategies, and action steps. The action steps are broken down into a) Community Assessment/Information Analysis; b) Development and Design; c) Implementation; d) Monitoring/Evaluation/Interpretation; e) Reporting/Documentation; and f) Diffusion/Sustainability. The person responsible, the time frame, and the resources required are detailed for each of the action steps. This data is also entered verbatim.

Training has been provided in operational planning. However, not all of the individuals on a community committee will have received this training. This may mean that some of the required steps to accomplish an objective have not been anticipated, resulting in an inaccuracy in the time allowed or resources required.
2.4 Analysis

Once the data has been entered into the HHIS it can be summarized at any point by Stakeholder, Initiative, Quarter, and Year. It is possible to use ACCESS to conduct some of the simpler analyses. It is possible to do sums, averages, minimums, maximums, counts, standard deviations and variances using ACCESS. As most of our data is qualitative in nature we tend to export the data sets for further analysis. This analysis is conducted on the summary reports using either NUD.IST for the qualitative data or SPSS and EXCEL for the quantitative data. In the case of quantitative analysis, most commonly frequencies, means, modes, ranges and standard deviations are calculated for data sets. When required further analyses are undertaken. Content and thematic analyses are used with the qualitative data.

3.0 Results

3.1 Operational Planning

The HHIS tracks the objectives, indicators, strategies, and action steps outlined in the Operational Plans submitted by Coordinators and the BC Heart Health Coalition. Annually a report is produced which requests information on the progress of any objectives whose due dates passed since the last report. This allows the Provincial Coordinator and the Principal Investigator to track the progress of the community initiatives. The Central Team can then best determine how to assist the communities or Coalition in meeting their goals.

3.2 Technical Support

The availability of the HHIS and the Database Administrator allows the Provincial Coordinator to provide assistance to the communities and the coalition as efficiently as possible. Data from Quarterly Reports has highlighted the need for support in the areas of planning and evaluation, minimal delays in funding and immediate responses by the Central organization to local conflicts. Each of these issues has been addressed by the Central Support team. Data has also been requested and used to enhance the sharing of information and key strategies between Demonstration communities. Following each quarter, Quarterly Report data has been rolled up for the entire project. In particular, information relating to influencing factors in other demonstration sites is of interest. Summary reports produced from HHIS including reach and recruitment of heart health activities, cash and in-kind contributions, products and publications have resulted in increased diffusion of project activities and enhanced planning for future activities. Feedback from one of the communities describes how the HHIS has been of assistance to them in "processing data from a Pilot evaluation, and providing data outcomes in easy to understand, useable terms for use at the local level and for comparison in the future".

3.3 Reporting requests

The reporting requests of NHRDP, the Canadian Heart Health Initiative Evaluation, and the BC Ministry of Health can be met through developing reports based on the data contained within the database. The HHIS was used extensively in meeting the requirements of the Canadian Heart Health Initiative Evaluation conducted in the Spring of 1996. A short time frame of 6 weeks highlighted the ability of the information system to provide timely, relevant data.

To date, the HHIS has provided the information for the production of regular and ad hoc reports based on the Project Quarterly Reports, Meeting Minutes, Activity Tracking Forms and the Operational Plans. For example, the research site visit review team requested an evaluation of technical support to the communities. To produce a report on the utilization and response to technical support the number of meeting minute actions assigned to technical support at Provincial meetings were counted and analyzed. Thus, the BCHHDP staff were able to report on the types of support required. Further analysis of the Quarterly Reports across Demonstration Communities determined the number of times Central Technical Support was cited as a positive influencing factor or a negative factor. Differences in community use of central technical support was also determined. Subsequent qualitative analysis demonstrated that planning and evaluation were key areas for support, that delays in funding resulted in negative impact at the community level and that immediate support in a conflict situation was necessary. Operational
decisions have been made based upon the reports produced by the HHIS and it has been possible for the Provincial Coordinator to track the progress of the communities through the provision of regular reports. The HHIS has also assisted in the development of publications.

4.0 Anticipated uses

4.1 Costs

The HHIS tracks both the budgets and financial records of the Communities and the Coalitions and the In-Kind Contributions for each Initiative. Plans have been made to develop a formula to calculate the financial value of the in-kind contributions and thus arrive at a figure which indicates the resource requirement of a particular initiative. Tracking of costs also allows for the determination of the proportion of leveraged funds from non-Ministry sources.

4.2 Health Impacts and outcomes

Through the tracking of the operational plans submitted by the communities and the Coalition it is possible to collect and compare the actual process and outcome data for the pre-selected indicators. This provides a means to measure the health impacts of the BCHHDP. For example, event tracking information is entered related to reach and recruitment, types of participants, fiscal expenditures, cash, in-kind and volunteer contributions, staff time, partners involved, event activities and lessons learned. The impact of each event on heart health knowledge, awareness and behaviours and client satisfaction is also evaluated. A comparison of the inputs, outputs and throughputs necessary to reach an intended client group and achieve a certain health impact (short term health outcomes) and the relationship of this to stated objectives is then possible. This information provides a solid basis for decision making prior to planning any new initiatives and will be instrumental in identifying effective intervention strategies for dissemination.

4.3 Program Performance evaluation

The HHIS stores both process and impact information which is then transferred into SPSS, EXCEL or NUD.IST for analysis. Reports are generated Quarterly, Annually and on an Ad Hoc Basis. This allows the BCHHDP to address the Ministry of Health Program Performance Evaluation standards which state that: "Monitoring and tracking systems or structures will be created so that progress towards the intended goals of the first New Direction "Better Health" can be assessed."[1] and that "The goal is established to balance providing the best outcomes with minimum cost and risk, and progress towards this goal is regularly reported to the defined community and funding agency."[2] HHIS allows for comparisons of processes and impacts over time and across sites.

4.4 Utilization Management

Similarly, HHIS is an important tool for a Utilization Management approach. A utilization management approach is based upon the key principles of using evidence to make decisions, documenting decisions, provision of relevant and timely information, coordination of health services and identification of appropriate use. The HHIS provides timely, relevant information for decision making and the planning and coordination of heart health initiatives. It addition, it documents the process and provides the information to assess efficiency.

4.5 Limitations

There are a few limitations to using ACCESS. To manipulate a large database efficiently one needs at least 8 megabytes of random access memory. This is especially important in developing the database and in creating reports. A form can only contain up to 50 questions before it becomes difficult to manage. Data from surveys containing over 50 questions are more appropriately entered directly into SPSS or a word processing package for transfer to NUD.IST.

The limitations of the HHIS relate mostly to the human ability to record data as fully and accurately as one would wish. When a number of different individuals in different locations are recording data about events, meetings, etc there is variability built into the data. Having a consistent database administrator responsible for data entry can help
eliminate some of this variability, however some will still exist. The other major limitation imposed upon the HHIS is the submission of data on a timely basis. If the data has not been received to be entered, reports cannot accordingly be produced on a timely basis. To be useful as a management tool the database must be updated on an ongoing basis and therefore requires continuous data collection and entry.

5.0 Summary

The HHIS has provided timely, relevant data which has met the current reporting and project management demands of the BCHHDP. Project managers are satisfied with the content and reports produced to date. Data has been used for research publications and Provincial and Community level decision making. The electronic database is superior to paper. It improves the management of qualitative data by minimizing space requirements and allowing comparison within and across sites on specified evaluation components during any identified time period. It collates related information into manageable units for analysis. Queries and reports are generated within very short time frames. Further analysis is still required. The entry and analysis of quantitative data is also efficient although analysis is limited to descriptive statistical techniques.

Subsequent to initial development of the database minimal training is required to enter data, run queries and produce reports. Reliability and validity of data are key issues in field research/programs that the database itself cannot resolve. A balance between pragmatic and theoretical issues in data collection must be considered for community health initiatives where a variety of individuals with varied skills, capacities and limited resources plan and implement health interventions. A key strategy which has resulted in enhanced commitment to evaluation in the BCHHDP has been immediate feedback of evaluation results. The HHIS allows for the provision of this immediate feedback.

The use of the HHIS for the production of final reports and publications is expected to increase as the BCHHDP enters its final year evaluation. Further demands will be placed on the HHIS. For example, the evaluation of resource utilization which has not yet been possible. The HHIS is an effective information system for project management when used in combination with other analytical packages.

References


Emerging Needs and Technologies

Chair: Larry Scott
"TeenNet": Using The Internet to Engage Teens in Health Promotion

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1. Abstract

Rationale: Teens are often captivated by information technologies (e.g., computer games). The increasing availability of the Internet creates innovative channels for tobacco prevention and cessation likely to reach a large number of young people. The goal of TeenNet is to take a "teens in action" approach to achieve an increased in the number of teens engaged in health promotion.

Method: Interactive technology components related to teen health and lifestyle issues are being developed for use in the classroom, community, and in the home. TeenNet consists of four main components that are housed in a World Wide Web site that uses the metaphor of a teens only island called CyberIsle. The components are: 1. CyberIsle Home Page, 2. Health Information, 3. Self-Assessment and Guided Change, and 4. HotTalk - peer-led discussion groups.

Results & Discussion: Piloting of the first prototype of CyberIsle will commence in May 1996. The technology will be evaluated with high school students in North York and in Brant County, and with street connected youth in downtown Toronto. Due to the involvement of youth in all stages of development and evaluation, it is anticipated that the first pilot will indicate that the Web site is graphically appealing to teens, is relevant to their needs, and engages them in investigating and discussing health issues.

2. Project Overview and Goals

New multimedia and interactive technologies (e.g., computer games) captivate teens, providing exciting and innovative ways of engaging youth in disease prevention and health promotion activities. In addition, the increasing availability of information technology (e.g., SchoolNet) creates an innovative channel for health education likely to reach a large number of young people (non-smokers and smokers), including those turned off by or disinterested in, traditional classroom programs.

Through the use of multimedia, interactive technology, the overall goal of TeenNet is to increase the number of teens engaged in smoking prevention and cessation, and other positive lifestyle behaviours. Multimedia, interactive technology components related to teen health and lifestyle issues are being developed for use in the classroom, community, and home. These components, accessed via the Internet, include:

- **World Wide Web Home Page**: gateway to all components, including an electronic magazine composed by teens. Using the metaphor of a teens only island called 'CyberIsle'

- **Health Information**: interactive, multimedia information on smoking and related health issues, as well as quizzes and interactive games

- **Self-Assessment and Guided Change**: assessment, individualized feedback and guided self-change strategies, tailored to readiness for change

- **HotTalk**: peer-led discussion groups on relevant health and social issues
This project will produce carefully-evaluated information technology programs that are effective for engaging an increased number of teens in smoking prevention and cessation. Community action methods will be used to engage hard to reach teens (street youth) at community locations (e.g., Drop-in Centres). The components can be widely and quickly disseminated across Canada and internationally via SchoolNet, local FreeNets and other links to the Internet. This will ensure ready access from classroom, home and community sites.

3. Basic Philosophy: “Youth Driven”

TeenNet underscores individual choice by teens and the exploration of options regarding health behaviour. TeenNet takes a "teens in action / youth driven" perspective that involves young people from diverse backgrounds in all stages of the program development and dissemination. The development of TeenNet is guided by five principles:

- **Participatory**: key involvement (ownership) at all stages by teens
- **Relevant to Teens**: focus on health, personal and social issues identified by teens
- **Autonomy Supporting**: encourages individual choice and exploration of options regarding health behaviour
- **Active Learning**: flexible and highly interactive, stimulates life-long learning
- **Fun**: engaging

The Web site uses the metaphor of a teens only island called ‘CyberIsle’. All health information, interactive quizzes and discussion groups will be accessed via various places on the island. The Home page is the gateway to all components. CyberIsle also provides access to the TeenNet Home Page which contains Smoke Free Class of 2000 lesson plans for teachers, hotlinks to relevant sites and discussion groups for teachers, health workers and parents.

**Welcome to CyberIsle**

Please visit our Web sites:

'CyberIsle' - [http://teennet1.med.utoronto.ca/welcome](http://teennet1.med.utoronto.ca/welcome)

and the TeenNet project site at [http://teennet1.med.utoronto.ca/teennet/](http://teennet1.med.utoronto.ca/teennet/)
4. Partners

TeenNet is based at the Department of Behavioural Science, University of Toronto and at COMMIT To A Healthier Brant, Brantford, Ontario. The collaborating partners involve a network of 12 organizations which are directly involved in education and smoking prevention, including:

- Addiction Research Foundation
- Brant County Board of Education
- COMMIT To A Healthier Brant
- Council For A Tobacco-Free Ontario
- Donwood Institute
- Frontier College - Beat The Street
- FSC Internet
- North York Board of Education
- North York Public Health Department
- Ontario Tobacco Research Unit
- University of Toronto
- North York Community Health Promotion Research Unit

These organizations have extensive experience and access to the target teenage population, including school leavers and street youth.

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Abstract:

In order to better measure and understand the needs of their communities, and strengthen the accountability of their programs, district health councils, public health units and the academic health sciences centres in Ontario have expressed the need for a health information source which is not only more efficient and accessible than those in existence, but would offer an "intelligence" component to assist with the planning of services, research and education. In response to this need the Ministry of Health undertook an initiative to establish a system of regional Health Intelligence Units across the province. Although each Unit is accountable to its partners in the region, they overall fall into three broad categories: data, information and intelligence. This presentation describes the experiences of one of them, the Central West Health Planning Information Network, in defining the priorities of partners and undertaking projects to meet them. In addition, the presentation includes a discussion of the development, testing and application of the Ontario Health Data Warehouse, an electronic data repository available by remote access for use in planning and decision-making.

1. Introduction

In 1994 the Ontario Ministry of Health requested proposals from five regions in the province for the establishment of a network of Health Intelligence Units. The concept for these units originated in the early 1980\'s with the work of Kerr White, who emphasized the importance of active collaboration between community health planners and academic health centres. Their function would not be to make policy decisions, but to increase the capacity of partner agencies to provide a better factual basis for decisions regarding allocation of resources, what services to provide, what to include in health professional education, and what research areas to pursue.

2. The Central West Health Planning Information Network

The partners in Central West Ontario include the seven public health units and seven district health councils located in the districts of Hamilton-Wentworth, Niagara, Waterloo, Haldimand-Norfolk, Wellington-Dufferin, Brant and Halton, and the Academic Health Sciences Centre of McMaster University who serve a population of over 2.1 million people. They recognized that even though they had complementary health planning capacities, these were not sufficiently overlapping, and that decision-making in the region could be improved. In their proposal for creation of a regional Health Intelligence Unit (H.I.U.), later retitled the Central West Health Planning Information Network (CWHPIN), they cited 9 values upon which it would be founded. These are:

1. A population-based health perspective: The H.I.U. values the population-based health approach to health decision-making. This includes a geographically-based approach for the Central West population of 2.1 million and an approach which recognizes the broad determinants of health (i.e., social and physical environment, lifestyle, genetics, economic well-being and health care services).

2. Enhancing the capacity of the partners to make the most effective use of information for the planning of population health programs, health and social services, and the education of health professionals. The H.I.U. places a high value on the enabling aspect of its work. Activities which enable partners to develop skills and enhance capacity
will be placed over other activities. Application of this principle will create sustainability of the capacities derived from the Unit among the partners.

3. Recognition of a diversity of needs and products. The unit values the unique needs of each of the partners, their diversity and the contributions they bring to the partnership.

4. Participation of other organizations. The H.I.U. values the participation of other education, health and social service organizations and agencies in the region. These organizations will be encouraged to participate in both utilizing and contributing to its activities through joint ventures.

5. Equity among the partners: The H.I.U. places high value on equity of access by all of the partners to its resources within specified criteria for prioritization and in recognition of resource constraints.

6. Collaborative ventures and communications: The H.I.U. values ventures which increase collaboration and communication among the partners with a view to developing a network.

7. Respect for autonomy: The H.I.U., while promoting collaboration and valuing joint ventures, respects the individual autonomy of each of the partners in their own decision-making as it relates to their local population health services needs and educational philosophies.

8. The value of evaluation: The H.I.U. values continual evaluation of initiatives and activities to provide further intelligence to enhance needs identification and prioritization, information dissemination, professional/skills development, and evaluation/research.

9. Value of local control: The H.I.U. respects the concept of local control both in terms of the governance role of each of the partner agencies and the need for local control of the generation of data and interpretation of the implications of that data for local planning.

3. Workplan

Based upon these nine values, four goals were identified for CWHPIN: 1) needs identification and prioritization; 2) information dissemination; 3) professional education/skills development; and 4) evaluation and research activities.

Once funded, the initial work of the Unit began with translation of its goals into a workplan for the first year. This was begun by conducting a survey of the partner agencies to determine their current capacity for electronic communication, and what they felt were the most important needs in the areas of needs identification, information dissemination, professional education, and research that CWHPIN might address. Results revealed a very uneven pattern of communications capacity, with some agencies already having local area networks and internet access in place, and others with an assortment of older and newer, unconnected machines. The first round of questioning about short and longer-term priorities produced a list of 115 suggestions, including the development of a common set of population health indicators, outcome standards for health promotion programming, increased collaboration among researchers, development of common data packages, computer training, qualitative methods, and internet connections. Using a qualitative data-reduction technique, this list was reduced to about five topics in each of the four areas which, during a second round survey, respondents were asked to rank in order of importance. This revised list was brought to a planning day during which all of the partners identified the work for the next year. Although there was a great deal of discussion, it quickly became apparent that there were three primary issues. First among these was the development of a network of electronic communications linking the partners to one another and the outside world. Second and third, however, was the creation of a shared framework for community needs assessment, and a common technique for identifying priority health issues, and the health intelligence to support them. These, then, formed the workplan for the first year of operation. Each of these two major topics is discussed in more detail by other presentations at this meeting. They, and all other projects, are undertaken by the entire Network, with every partner being responsible for their successful completion. Criteria have been created for the identification of new initiatives, and a "Team Risk" approach applied.
In support of its partner agencies, CWHPIN develops and provides:

1. Health Data: to improve the quality, relevance and accessibility of population health data available to partners;

2. Health Information: to improve the ability of the partners to analyze, present and use population health data;

3. Health Intelligence: to improve the ability of the partners to use health information in planning of health services, education and research, and

4. Skills Transfer: to enhance the knowledge and skills of the partners.

4. The Ontario Health Planning Data Warehouse

One important new tool for accomplishing these is the development by the Ontario Ministry of Health (Information, Planning and Evaluation Branch) of a Provincial Planning Data Base. The goal of this data base, of which the Health Data Warehouse is part, is to construct a data base to enable strategic decision-makers, on a provincial or local level, to analyze population needs, configure health systems, and evaluate service utilization and outcomes. The data base, which incorporates multiple data sources, is to be supported by appropriate data management technologies and tools for end-user analysis.

The objectives of the data base are to:

- strengthen planning and strategic decision-making by improving the quality of data used, expanding the breadth of relevant data sources available and reducing the time to acquire data;

- increase the use of information in policy and planning activities by making data and information, in particular large provincial datasets, directly available on-line to a greater number of authorized planners and decision-makers;

- to enable system-wide planning by integrating data sets across health sectors and programs;

- to ensure consistency, timeliness and relevance of data to different levels of planning and strategic decisions by managing a single source data base which incorporates a variety of types of data (e.g., survey, pictures, maps, qualitative, quantitative);

- to increase the skills of planners in the analysis and application of information in planning by designing the data bases to facilitate learning and by providing training in the tools, structure and attributes of the database.

The Data Warehouse currently is under construction, with pilot testing and evaluation being carried out both by Ministry and staff and others from a number of remote sites in health units, district health councils and at CWHPIN central office. Data bases being tested include the Canadian Institute for Health Information Standard Master File, Statistics Canada Vital Statistics files for Ontario, the Ontario Health Survey, the Ontario Registered Persons Data Base, Ontario Home Care Administrative System, Integrated Homemaker file, population estimates and projections, postal code conversion file, Case Mix Group Reference File, 1991 census, and Day Surgery files. The data base is estimated to contain about 20 gigabytes (GB) of operational data, and nearly 30GB for overhead. All information resides behind a secure firewall, and remote sites are linked to provincial mainframe computers by dedicated lines. Individual records can be linked across time and space by use of unique, scrambled, identifiers. Tools being evaluated include GQL, Analysis, and Knowledge Seeker. After pilot-testing has concluded the Health Intelligence Units, including CWHPIN, will be involved in providing training to the staff in their partner agencies.
5. Summary

Health Intelligence Units in Ontario represent an attempt to improve the quality of decision-making in health units, district health councils and universities regarding health planning and programming. The success of the units, however, will depend upon the questions posed by their partners, and their willingness to use health information to guide them. The approach being taken by CWHPIN to help ensure that this will happen is to first improve their capacity to use information in community needs assessments, program planning and evaluation. This is being accomplished through application of the Needs Assessment/Planning Framework. By addressing concrete situations, their staff are developing the ability to pose questions, identify appropriate data sources, and utilize advanced techniques for data analysis and presentation. Current applications are in the areas of long term care planning, mental health reform, tobacco use prevention, and food safety. Based upon the experience gained from these projects, CWHPIN hopes to build a model of health in Central West Ontario that will be able not only to respond to issues after they have been brought to the political agenda but, through a program of active surveillance, anticipate the need for policies and programs. Plans are underway to evaluate if, and how, this improved access to information influences the quality of decision-making in the region.

6. References


Community Health Information Systems: Continuing Care Data Warehouse Project (CCData) “Doing more with what you have!”

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Abstract

Continuing Care involves the delivery of services to eligible people living at home or in a facility. Services include: long term care case management, home nursing care, residential services, community rehabilitation (Occupational and Physiotherapy), social work, a quick response program for intensive short-term care, adult day care, community supports for independent living, delivery of prepared meals, homemaker assistance, respite services and contact with community groups. Client and service information is collected and stored on Continuing Care’s provincial on-line system developed principally for financial purposes but also used for operational needs.

The Continuing Care system produces a variety of reports but, the reports may not always meet specific needs of a health unit. Changes to reports require time because all health units must be consulted. The CCData project was an attempt to:

1. Provide access to the mainframe data.
2. Allow more timely response to ad hoc questions.
3. Allow flexibility in producing reports suited to individual needs.
4. Provide a set of standard queries for general use.

As a benefit of this system, health units will be able to see where their data entry can be improved to provide better quality management reports.

To realize this project, a client-server system was developed to receive extracts of the mainframe data. The database is available to Ministry staff in Victoria by means of the local area network. Health unit staff access the database through HealthNet BC, a service of the Information Technology Services Division (formerly BC Systems Corporation). The software used (both on the client PCs and the server) is commercially available.

The presentation will review the history and project details resulting in the development of CCData. We will also report on the data, procedures used to maintain CCData, technical specifications, the users and their particular needs, (health unit vs. central office), type of reports being created with CCData and, in general, the benefits and drawbacks of CCData. We will also talk about how CCData may be used in the future.
1.0 Introduction

How can healthcare agencies perform more efficiently? How can patient/client, service, and outcome information be shared quickly and accurately between staff in different locations across the province? How can programs and outcomes be analysed?

Information systems (IS) and information technology (IT) must provide people with the information they need to perform their jobs - gathering information, making decisions, planning actions, recording and reviewing results, and starting these activities all over again. IS/IT development offers electronic and computer-based methods to help achieve the goal of a more efficient and effective continuum of care. Computer technology and business process re-engineering can assist in answering the above questions, and the Continuing Care Data Warehouse Project is an example of such business process innovation and application of technology.

2.0 Business Problem

The Continuing Care Division (CCD) of the British Columbia Ministry of Health is comprised of community home care nursing, long term care case management, and rehabilitation therapy services. Direct staff services (nurses, therapists) as well as management of other services (residential facility placement, home support workers) are provided. Client and service data has been collected on a provincial mainframe system developed for operational and financial purposes rather than flexibility in management reporting or on-line analysis.

Prior to the introduction of CCData, only the systems analysts in Systems Division were able to retrieve data from the Continuing Care Information System (IMS database). Staff in the Ministry of Health (Victoria), health units and external users (e.g. Ministry of Finance and University of British Columbia) relied upon scheduled reports or submitted service requests for ad hoc reports. Depending upon the complexity, the turn-around time for ad hoc requests ranged from a few days to several months. Later, IBM’s Query Management Facility (SQL) permitted staff in Systems Division and Data Services Branch to write queries for ad hoc requests.

Other staff in Victoria and the 21 health units across the province (16 provincial health units and 5 municipal health departments) reported dissatisfaction with the length of time required to receive reports. The timeliness, accuracy, format and usefulness of the Continuing Care reports needed to be improved.

3.0 Continuing Care Division Data Warehouse Solution

International Data Corporation (IDC) Canada, a technology research company, describes data warehousing as follows:

"At its most fundamental level, a data warehouse is a staging area for decision-support information. It collects data from various applications in an organization’s operational systems, integrates the data into a logical model of business subject areas, stores the information in a manner that is accessible and understandable to non-technical decision makers, and delivers information to decision makers across the organization through various report writing and query tools."

The development of CCData is consistent with this definition, allowing the data to be more readily available to those who need it. While the data is gathered and stored as it has been, CCData hardware and software allow that data to be extracted from the Continuing Care Information System and transformed into structures reflecting business areas: e.g., clients, direct care service plans, assessments, waitlists, etc. This information is available to health units in the province and Ministry staff in Victoria.
3.1 Project Organization

The project was organized with a steering committee to ensure that the project objectives were achieved, review deliverables, resolve problems, and provide approvals and project sign-off. Reporting to the steering committee was the project manager who, with the representative from Continuing Care Systems Division, formed a project management team to coordinate the activities of the working group and various teams. The working group consisted of eighteen members; five from the participating health units and thirteen from Continuing Care Division. Additional support was given by the Ministry's Data Management Branch and Computer & Network Services.

3.2 Goals and Objectives

The goals of the CCData project were to:

1. Provide access to the mainframe data.
2. Allow more timely response to ad hoc questions.
3. Allow flexibility in producing reports suited to individual needs.
4. Provide a set of standard queries for general use.

As a result of these goals, health unit management and other users may learn more about the quality of the data entered at the health unit level and take appropriate action if deficiencies are found.

Five project phases were detailed after initial discussions in January 1994:

<table>
<thead>
<tr>
<th>Phase</th>
<th>Task</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Local area network development</td>
</tr>
<tr>
<td>2</td>
<td>Office automation</td>
</tr>
<tr>
<td>3</td>
<td>Ad hoc query/reporting</td>
</tr>
<tr>
<td>3a</td>
<td>Financial data</td>
</tr>
<tr>
<td>4</td>
<td>Standard queries and report library</td>
</tr>
<tr>
<td>5</td>
<td>Decision support system</td>
</tr>
</tbody>
</table>
3.3 CCData Business Model

Representatives from the Continuing Care Division, health units and Systems Division met in joint application design (JAD) sessions to review the business of Continuing Care. This led to the development of a set of business questions and a data model.

Figure 2 - CCData Business Model
3.4 Technology Involved in CCData

CCData involved installing a local area network (LAN) in Continuing Care Division; however, a LAN is not a prerequisite for accessing CCData in CCD. It should be noted that Continuing Care Division is located in a building a short distance from the principal Ministry of Health building (Richard Blanshard Building). Pilot sites were set up in five health units in addition to the initial users in Continuing Care Division. A database server was set up. Software was chosen and installed on client PCs to enable users to connect to the network and query CCData from either Continuing Care Division or the health units.

3.4.1 Technical System Description

CCData is a DEC (Digital Equipment Corporation) Alpha 3000 with 128 Mb of memory (RAM), 7 Gb of disk space (DASD) running OSF/1 version 7.1 (Unix). The database management system is produced by Oracle. This database server is connected to the Ministry LAN in the Richard Blanshard Building. The LAN in Continuing Care Division is connected to the LAN in the Richard Blanshard Building by a T1 line routed through the Information Technology Services Division (ITSD; formerly BCSC). This server is not used solely by Continuing Care but is shared with Regional Performance Analysis (formerly Information Systems-Inpatient Services).

Users in health units connect to the ITSD by means of SpanBC (the provincial network infrastructure) and then by T1 as noted above. The minimum configuration for a client PC is a 486 microprocessor, 50 MHz, 8 Mb RAM, and 450 Mb hard disk drive. All client PCs use a communications program which follows TCP/IP protocols (e.g., NetManage Chameleon). Queries composed using Microsoft Access are translated by an ODBC (Open Database Connection) driver into commands recognizable to Oracle. Each PC also requires certain Oracle programs (SQL*Net) used in establishing the connection. Continuing Care Systems Division staff also use Telnet to establish a connection with the server. All programs on the client PC require Microsoft Windows.

As noted earlier, all data entry by health unit staff is performed on the Continuing Care Information System. Each month, extracts of the mainframe data are taken and then loaded into Oracle tables. This is not an incremental process, rather each table is completely refreshed.

3.5 Data Warehouse Tables

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<td>Client History</td>
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<tr>
<td>Diagnostic</td>
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<td>55,389</td>
<td>monthly</td>
</tr>
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<td>Direct Care Service Plan (Home Care Nursing &amp; Rehabilitation)</td>
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<td>Group Home Claims</td>
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<td>2,470</td>
<td>monthly</td>
</tr>
</tbody>
</table>
3.6 Other Components

Training is always an important part in the development of new systems. To help the new users, three training sessions were held in Victoria and one in Vancouver. Each session was two days long. The session held in Vancouver was attended by the primary users from each participating health unit and their backups. The training was a customized Access course based on Continuing Care data.

Another important aspect of this project was the data dictionary, written with the novice end user in mind and deliberately kept non-technical. The field names were created to be as close to English as possible with standard naming conventions. Historical information was added to explain changes to codes or definitions over the years and any new data related to new programs or services.

In the initial design of CCData, views of client data were designed allowing users to see either all of the client data or a limited FOI (Freedom of Information) view. This last view is termed an FOI view as it restricts the viewing of a client’s Personal Health Number, name, address, telephone number, GAIN number (Guaranteed Annual Income for Need), contact name, and contact telephone number. The view assigned to users depends upon the nature of their work. Also, to allow more efficient queries, views of the data were designed for each participating health unit where data was selected according to geographical parameters. This allowed a health unit to query program data for its own services and area rather than sort through the entire provincial database.

A query library is being developed. Two collections of queries are available dealing with assessments and paid claims. Examples of assessment queries are: Assessed client care levels by case manager; and Case manager visit totals for a specific time period. Examples of paid claim queries are: Paid homemaker hours by month; and Homemaker clients exceeding policy maximum.

4.0 Discussion

4.1 Benefits

The CCData application of distributed client/server technology allows users direct access to data. Significant benefits include productivity increases for health unit and Continuing Care Division analysts, more timely service to managers requesting ad hoc reports, ability to format reports based on individual needs, improved understanding of program data quality and processes, and increased availability and quality of program information.

A reduction in time taken to prepare historical utilisation analyses of Continuing Care services and clients, and strategic plans has been reported by users. One user reports that before CCData a particular analysis required one month; now, that same work can be accomplished within a week.

As noted above, CCData allows reports to be formatted differently. In the past, agreement or consensus amongst health units was needed in order to make changes to a scheduled mainframe report. Now, a health unit can do this individually to meet local needs (e.g. segmenting data by sub-office or postal code).

Reports produced by CCData may show errors or omissions in data collection and entry at the health unit level. This may allow health unit management to review processes and make appropriate changes to improve data quality.

4.2 Critical Success Factors

1. Sybase Corporation describes the following success factors for data warehousing. These factors characterize the planning and successful activity of the CCData project over the last three years:

   • define business objectives
   • define business architecture
   • start small in one project area
   • deploy, monitor, tune, and maintain the data warehouse
2. Availability of knowledgeable people in field health units to use CCData.
3. Commitment by senior management of people and resources for CCData pilot project.
4. Stakeholder participation in all project phases.

4.3 Concerns

Can this one application satisfy the needs of all health units in the province, given the differing resources available in each? For instance, health units without research officers and suitable PCs continue to rely on paper mainframe reports.

Aside from the initial training sessions mentioned above, there has been no further training in CCData. New users must take training in Microsoft Access on their own and already have some familiarity with the Continuing Care data or learn it on their own. Microsoft Access is not a difficult program to learn but training is required and, as in so many learning situations, frequent use helps to reinforce the lessons learned and build confidence. Along with the important point of training is the need to understand the data. This may be more challenging than learning the software.

The flexibility of CCData may make it difficult to compare similar reports between health units. That is, the methods used to manipulate data and produce results may vary between users.

5.0 CCData’s Future

Expansion of CCData has started and will continue. From the initial pilot sites, there are now eleven health units using CCData (approximately half the number of health units in the province). Some large health units in the province may be able to apply resources to further information systems development in their regions and derive more benefits. Other technological innovations may be explored, such as regional and provincial database integration, e.g. electronic upload/download from a regional computer system to the Continuing Care Information System. It is possible that larger health units or regions may develop independent databases focused on their operations and reducing their dependence upon the provincial database (i.e. CCD IMS). This development would have direct implications for CCData and its usefulness to all health units.

CCData still has potential to become the basis for a more complete decision-support system (DSS) for field managers; a development which may minimize the need for support staff to run certain routine reports or queries used in planning or monitoring the work of the health unit.

The financial benefits of CCData could be evaluated in more depth. IDC Canada describes recent financial results after surveying 45 companies from North America and Europe that have implemented a data warehouse through 1995. The average three-year return on investment was 401%, ranging from 3% to 1838%. The average payback for the data warehouse was 2.3 years on costs that averaged $2.2 million (US). Certainly some firms in some industries have found tremendous results in data warehousing.

A useful area of analysis provided by IDC Canada was the categorization of benefits attributable to the data warehouse. Savings were made in three classes: Keepers - Savings found by not keeping data the way it used to be kept accounted for 20% of benefits in the study; Gatherers - Savings found by gathering data for decisions in a new way accounted for 30% of benefits; Users - Savings found through actual use of the data warehouse where it was the sole source of information accounted for 50% of identified benefits. This benefit breakdown suggests a strategy or framework for evaluation of CCData financial benefits.

After CCData was made available, all pilot users were sent a survey. The results were encouraging and, following many suggestions, resulted in a Users’ Group being created. The Users’ Group is seen as a forum for education, discussions and initiating future developments. Further success of CCData and its expansion may require
improvements to server hardware and software as the system’s capacity is tested and strained by additional users. Will a cost/benefit analysis indicate approval of the funding required for such an expansion?

6.0 Conclusion

Complex organizations with large numbers of clients require efficient and effective information systems. A data warehouse, responsive to the need of timely information tailored to particular circumstances, can be an asset to the work of analysts, managers and line staff. This type of support is an essential requirement in the current and future healthcare environment where better and faster decisions are required.

CCData is a successful pilot to redesign management information processes and products, and test enabling technologies. Data warehousing is one alternative that needs serious consideration in the effort to build information systems that support the evolving healthcare system in British Columbia.

7.0 References

DIABCARD - A Smart Card for Patients with Chronic Diseases

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Abstract

Within the EU-sponsored project DIABCARD the core of a chip card based medical information system (CCMIS) for patients with chronic diseases exemplified on Diabetes mellitus has been developed. The long-term goal of the project is to improve the medical record and the quality of care for patients with chronic diseases. The basic idea is to have a portable electronic medical record on a smart card. This will improve the communication between the different healthcare personnel and between different institutions and at the same time promote shared care. The DIABCARD CCMIS will offer controlled access to the necessary and up-to-date patient record to everybody involved in the patient's treatment and it will help reduce the constantly rising health care expenditure.

The system has been implemented in a first "small" version. The system architecture contains hardware, software and orgware. It considers especially the memory of the chip card, the processor, the data structure, security functions, the operating system on the chip card, the interface between chip card and application and various application areas. The DIABCARD dataset was defined via an information model which describes the different communication processes, via acknowledged diabetes datasets and via medical scenarios. It includes amongst others emergency data, data for quality assurance and data for blood glucose self-monitoring. A first prototype has been developed and a pilot was run for three months.

1 Introduction

The costs for health care are constantly rising. In most western European countries health care expenditure accounts for 10% of the gross national product and doubles approximately every 10 years. Changing lifestyle and an increased life-span make chronic diseases responsible for at least 50% of these costs. Chronic conditions show some characteristic features: They typically consist of a number of different diseases. Therefore the patient is treated by several health care providers, the patients' medical record is usually distributed at various locations, examinations are often unnecessarily performed more than once; and the physician cannot provide optimal care as he/she is missing vital information. Information technology is being set up for improving the care of people with chronic diseases including medical decision support systems as well as health record systems.

DIABCARD is based on the idea of a portable patient record. This means that the physician who is eligible can access necessary and up-to-date information on the patient's state-of-health whenever and wherever he/she needs it. The technology used is a smart card. The system is being exemplified on diabetes mellitus.

2. Medical Background

Diabetes mellitus is a "typical" chronic disease. It affects 5-7% of the European population with an increasing tendency. It causes significant reduction in the quality of life and also in life expectancy. It accounts for at least 10% of the countries' health care budgets. On the other hand, it could be demonstrated that proper treatment can substantially reduce the progression or even onset of secondary diseases and complications [1] and lead to substantial "savings" of health care budgets [2].
In 1989 representatives of government health departments and patient organisations from all European countries met with diabetes experts under the aegis of the European Regional Office of the World Health Organisation and the International Diabetes Federation and set up the "St. Vincent Declaration". Recommendations and targets for improving life and health of people with diabetes by reducing morbidity and mortality were set up. Quality assurance to be performed on a local, national and European level is a major part of the St. Vincent Declaration [3]. Quality indicators were designed and constitute the DIABCARE dataset, laid down in the Basic Information Sheet (BIS). Via the BIS, data for quality assurance is collected on an annual basis using paper. The use of the DIABCARD system will facilitate and make collecting the necessary data more efficiently, i.e. provide better quality at lower costs.

3. Health Cards in Europe

The use of chip cards in health care has become an important issue in Europe. Clinical documentation in the coming years will be a complementary function of chip cards in connection with the utilisation of the chip card as proof of identity and authorisation. In Germany, about 80 million insurance cards have been introduced nation-wide, 120 000 card readers have been issued. In France 38,000 'Cartes de Sante' are currently in use, by the year 2000 all French citizens will have been equipped with a health smart card containing as in Germany, administrative data only and by 1997 all French health care professionals will have been issued a 'Health Professional Card'. This means that in France and Germany the infrastructure for smart cards has been prepared and that people are quite accustomed to the use of health cards. Another "side-effect" is that it has prompted the use of doctors' office computers. The number of doctors' office computers in Germany has risen by more than 150% since the introduction of the Health Insurance Card. Still, there are only few systems that deal with medical data [4].

4. DIABCARD

DIABCARD is a project sponsored by the European Commission which is developing, implementing and validating a chip card based medical information system (CCMIS) for people with chronic diseases. At the centre of the system is a smart card - the DIABCARD.

The project has been running for 4 years and is now entering phase III. Phase I dealt with the development scheme, the specification and the evaluation scheme. In phase II the project team concentrated on a first prototype with limited functionality which was implemented and tested at a hospital in Barcelona, Spain. At present the main emphasis in the third phase is on promoting interoperability with other health cards, on speeding up standardisation and on evaluating the present system in different health care settings all over Europe as the health care systems vary considerably from country to country and sometimes even from one region to another.

For the moment, the DIABCARD project is concentrating on diabetes mellitus. Its main goal is to improve the quality of care in diabetes mellitus and the quality of life of the patient with diabetes. The system is, however, designed in a way that can easily be extended to other chronic diseases.

Some characteristic features of the architecture are
- it sees the patient at the centre of the system;
- the basic communication model consists of different types of workstations; the communication channel being the card; the DIABCARD CCMIS is designed to be used in hospitals and institutions, in primary care, public health, and supporting activities;
- the system can also be used as a stand-alone system;
- the architecture is open; the system can easily be integrated into existing information systems and different networking environments;
- it is adaptable to technical advancements of the chip card;
- its specifications are not limited to diabetes mellitus, but adaptable to general health care data;
- a language module for European use has been included in the specification;
- it offers a high degree of security, data protection, privacy and integrity; there will be a patient health card and an access card for physicians;
existing standards have been integrated.

A high level application interface (API) is being defined within the project which relieves application programmers from handling smart card specific problems like communication and security protocols, card versions, local or remote access and performance optimisation. It is planned to make provisions on the smart card for regional administrative data as well as for smart card related data for DIABCARD evaluation and quality control. This interface will be provided on the necessary platforms to allow for easy integration of DIABCARD applications in GPs, departmental and hospital information systems. Value-added services, such as integrated scheduling and booking systems, patient referrals and prescription handling could be included. This is being developed by IBM Entwicklungen Deutschland GmbH, who is developing software for chip card applications (e.g. banking cards) worldwide in close cooperation with the EUROCARDS and G7 Health Cards initiative.

5. The DIABCARD Data Set (DCDS)

As mentioned above the chip card itself can be considered a portable patient record. To have widespread applicability the common European health record must be independent of hardware, operating system, application, and language (including national languages, term sets, coding and classification systems). Part of the solution was found to be a comprehensive, applicable and interoperable data set.

The DCDS consists of administrative, socio-demographic data and medical data items. The administrative data is mainly based on results from other projects. Medical scenarios, existing data sets and data items needed for the pilot test served to define the medical data set of the DIABCARD data set. Every data item is labelled with date observed; observer; originator (storer) and date of storage (timestamp). Existing and emerging standards have, as far as possible, been integrated. The DCDS is adapted to managerial needs in the context of shared care.

To enforce interoperability, the DCDS has been made compatible to datasets from related projects, e.g. DIABCARE, as in a first step on item level. A hierarchical tree structure was chosen for structuring the data items. This provides the basis for the application software and at the same time the data structure for the terminology glossary, which will at a later stage be added to the DIABCARD software program.

Version 2.0 of the DCDS is available. It has been implemented as a meta-database using a standard SQL-database tool and constitutes the DIABCARD repository. The relations of single data items are also key features in this repository. For an easy survey of the data items, the DCDS has also been implemented in a screen oriented interactive information system.

Most medical items have been widely agreed upon and have been validated in the first DIABCARD pilot that took place in Barcelona. The DCDS Version 2.0 will be evaluated in the various pilots with their differing functionality to be performed within DIABCARD resulting in a new and improved version.

6. The DIABCARD Implementations

The first DIABCARD implementation took place in a hospital, the "Hospital de la Santa Cruz y San Pablo" in Barcelona from July to December 1995. Three hospital units (Endocrinology, Obstetrics and Nephrology), that are housed in different buildings and in no way electronically connected to each other, participated in the pilot. The objective of this pilot test was to demonstrate the feasibility of the system and to get indications on the users' acceptance. It was therefore not necessary to build a complete system, but sufficient to integrate part of the functionality into the prototype. For various reasons an existing system (the Diabcare system) was adapted. Due to very limited funds, this demonstrator was then further adapted to serve the minimum needs of the pilot site. The Diabcare system was supplemented by management tables, medical data, report and card functions. This meant that additional relations were added to the existing database and a consultancy paradigm included. The system, designed and sponsored by Boehringer Mannheim, is called Diabcare and is an easy-to-use and easy-to-learn tool.

A first implementation of the prototype was run for 1 month. The redesigned and revised implementation constituted the 3 month pilot phase. One hundred and three diabetic patients, representing the different diabetes characteristics, participated in the test. The patients were randomised into one group using DIABCARD and one using paper records.
as before. The data transfer between the three units was handled using the chip card. At the end of each visit the physician and the patients filled in questionnaires. A total of 384 visits were recorded and evaluated.

The results showed that the system is feasible but that efficiency and functionality of the system need to be improved. The prolonged consultation time and missing functions, e.g. the automatic printing of transfer forms - lowered the acceptance of the physicians. Considering that before the test only hand-written records had been used and that only part of the functionality had at this stage been implemented, this result was to be expected. The patients, on the other hand, were very pleased with the system.

Another two tests are ongoing at the moment. One taking place in Italy, where the card communicates between General Practitioners situated in small country towns and a Diabetes Centre in Perugia. The other one is based in Athens, where home care has been integrated. It also involves other health care professionals, nurses, dieticians, and social workers.

At the moment these two pilots are concentrating on assessing feasibility and acceptance of the system. The first, small scale implementations are vital when the health care systems vary so much. On the other hand, it is also necessary to have a well functioning system in order to motivate potential participants in larger pilot tests. In the coming years the test runs in Athens, Barcelona and Perugia will be enlarged. Other pilots are being organised in Vienna, Austria; Corbeil, France; Thessaloniki, Greece; and Kassel and Munich, Germany.

7. ByMedCard

The Munich pilot test "ByMedCard" will demonstrate how a wired health network and health smart cards can complement each other.

The Bavarian Government is introducing a wired communication network. The project is called "Bayern Online" and consists of various subprojects. One of these subprojects deals with setting up a Bavarian Health Net. "ByMedCard" is one activity sponsored therein.

The pilot test in Munich will start at the "Innenstadt Klinikum", a university hospital, equipped with an in-house network. In the first step the concept of the Barcelona pilot will be used: several hospital units - housed in different buildings will be involved. Additionally, a GP will participate in the pilot study. The hospital network will at this stage only be used for teleconsultation between the department of Diabetic Footcare and Surgery.

In a next step the patient card will be equipped with pointers to existing medical records to allow fast and patient controlled access over the network. At the same time, the card's use as an emergency card will be prompted - enforcing interoperability with the above mentioned related projects.

Another part of "ByMedCard" deals with the development of an access card for health care professionals.
8. References


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Supporting Physician Needs

Chair: Tom Abernathy
Clinical Practice Guidelines and Decision Support Technologies: 
Assets and Liabilities in Common

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Keywords: Expert Systems, DST (Decision Support Technology), Practice Guidelines

Abstract:

Any effort to utilize medical Decision Support Technology (DST) will be based on implicit or explicit
STANDARDS of medical care. Such standards to guide the clinician in decision making can be established by
combinations of tradition, inertia, randomized controlled trial, consensus, legislation, and lassitude. Presently, no
more than 20-30% of medical procedures and therapies are supported by well-designed clinical study or other hard
evidence. Most standards or guidelines for clinical care as might be applied through DST will, therefore, be
necessarily based on weaker foundations. Developers of clinical decision protocols, algorithms, or specific hardware
and software must be cognizant of this, as well as other theoretical aspects of practice guidelines. Such individuals
would also benefit from knowledge of the empirics of guidelines' development and use, their historical context, and
their legal implications for both developers and users. This paper serves to explore each of these issues.

1. Introduction

Any effort to utilize Expert Systems or other Information Technology in clinical decision support will implicate
medical standards of care. Such standards to guide the clinician can be established by combinations of randomized
controlled trial, consensus, legislation, tradition, and lassitude. Presently, no more than 20-30% of medical
procedures and therapies are supported by well-designed clinical study or other hard evidence. Most clinical care
standards or guidelines as might be applied or "activated" by Decision Support Technology (DST) will, therefore,
be necessarily based on weaker foundations. Any domain expert enlisted to develop or refine clinical DSTs should
nonetheless be thoroughly familiar with the standards of his or her field of practice. Developers of clinical decision
protocols, algorithms, or specific hardware and software should be cognizant of the theoretical aspects of practice
standards, their historical context, the empirics of their development and use, and their legal implications for both
developers and users. The reader will perceive that the history of the development of clinical DST shares many
parallels with the evolution of clinical practice standards.

2. Definitions

The terms Practice Standard, Clinical Practice Guideline, Clinical Pathway, Critical Pathway, Practice Parameter,
and Clinical Policy all refer to written instruments used to assist in the process of clinical decision making. While
these terms are often defined to emphasize differences between them, they are largely interchangeable and the
customers use the term guideline in lieu of others. The National Academy of Science Institute of Medicine (IOM)
defines practice guidelines as: "systematically developed statements to assist practitioner and patient decisions about
appropriate health care for specific clinical circumstances." There is less variability in defining the legal "standard of care" which all physicians must exercise towards patients. Generally, such is described as that care "which a similarly trained physician would ordinarily exercise in a similar
case, under like circumstances in the same or similar locality,"5 or "that care and skill possessed by a reasonably prudent physician."6

Practice guidelines and legal standards of care are, therefore, not identical.7,8 However, one can consider a particular guideline and pose the question: How is the care articulated in the guideline not the standard of care? One answer, perhaps, is that while the guideline may articulate one standard of care, such may not be the only one. Recent efforts by several of the United States at legislatively equating practice guidelines with standards of care further blurs previous distinctions between the two, and will be discussed in this paper's sections on Liability and Legislation. The extent to which Expert Systems and other DSTs might themselves be able to establish or shape standards of care is a provocative future issue. Assessing the validity of some DSTs is, itself, made difficult by the frequent absence of clinical "Gold Standards."9

3. Historical Background

Development of the first guidelines is credited to the American Academy of Pediatrics who issued such more than 50 years ago.10 U.S. Government involvement in guideline utilization took a significant step forward in 1972 with the creation of Professional Standards Review Organizations (PSROs) which were established to assess medical appropriateness and necessity of care provided to Medicare and Medicaid recipients.11 As government exercised its legitimate interest in limiting medical costs, so subsequently did private payors.12,13 The algorithmic nature of many guidelines allowed for their formulation as decision support software.14

The concept of outcomes-based analysis is new neither to DST nor to medicine.11,15 In 1989, the Agency for Health Care Policy Research (AHCPR) was established in the U.S. Department of Health and Human Services to oversee the development of guidelines and to specifically develop measures to "reduce clinically significant variations" in practices and outcomes.11 AHCPR is empowered to contract with private entities in discharge of its responsibilities. Recent interest in AHCPR activities can be gauged by the number of recent "visits" to its web site; such have averaged as high as 100,000 per month.

In the latter years of the last decade, the American Medical Association (AMA) created a Practice Parameters Partnership and a Practice Parameters Forum wherein medical specialty societies and other organizations could collaborate and, to a degree, standardize the process of guideline development. The subsequent promulgation of practice guidelines by medical societies and other organizations has been likened to a "deluge."16 The current AMA "Directory of Practice Parameters" lists approximately 1,600 publicly available guidelines issued by more than 70 organizations.17 Upon inclusion of additional private and governmental/regulatory promulgators, one publisher has compiled a listing of 26,000 health care "standards" issued by organizations numbering 620.18 The promulgation of so many standards bespeaks a need for information technology merely to manage their overwhelming numbers, not to mention more substantive assessment of compatibility or conflict among them.

4. Current Status and Acceptance

Nearly all participants in the health care system are impacted by guidelines. Included among these are practitioners, patients/consumers, attorneys, arbitrators, courts, payers, researchers, government agencies, medical specialty societies, and medical malpractice insurers. Interest in guidelines among medical malpractice insurers has heightened.19,20 Some utilize a system of "carrots and sticks" with their insureds, linking guideline compliance with premium rates.21 With costs of U.S."defensive medicine" estimated to be as high as $15 billion per year,1 utilization of practice guidelines could make both risk management for the practitioner/insurer and resource allocation for the managed care organization (MCO) wiser and less random.19

Physicians and other clinical practitioners have been and continue to be a source of much resistance to the use of guidelines.12 Clinical academicians are particularly disdainful of perceived "cookbook" aspects of
Concerns are raised that a guideline "casting in stone" a treatment standard risks the stifling of medical progress, and that demoralization in the medical profession may result as the "art of medicine" is thereby usurped. The "value" of a particular test to a given physician may be much greater that the true utility of a test in answering a particular question and thus be "justified" as being part of this art. Further concerns relate the loss of personal interactions and the doctor-patient relationship as well as loss of control in the clinical decision process. It is only through the verification and validation of practice guidelines or of DST that greater physician acceptance may be attained. Collaborative efforts between physicians, other clinicians, and developers will further maximize chances of such acceptance.

More concrete criticisms of guidelines can be launched by citing studies where guidelines were outright ineffective in achieving their goals. Whether guidelines actually alter physician behavior has been described as "the million dollar question." It is probably MCOs that have the most powerful "incentive" for physician compliance at their disposal; the threat of "comply or be fired/excluded" may be a cause for concern for such employed or affiliated physicians. If a guideline is poorly designed or excessively complex, outright logical inconsistencies in its decision trees may occur, rendering the guideline invalid on its face. It is argued that guidelines unsupported by definitive study (e.g. randomized controlled trials) are nothing more than perpetuation of opinion. This is indeed true, but it is precisely for those medical issues for which no definitive studies have yet been done that need is greatest for formalized evaluation of the available (albeit suboptimal) evidence.

5. Soundness Attributes

Clinical Practice Guidelines should be more specific than general medical textbooks in detailing recommended treatments. Those recommendations based on hard evidence should be clearly distinguished from those based on expert consensus opinion. Additional specific desirable attributes of guidelines and of the guideline development process have been enumerated by the IOM/AHCPR, the AMA, the Canadian Medical Association, and others (see Tables 1 and 2 at end). The extent of resources (money) spent in the development and promulgation of a guideline may indeed be an additional, albeit indirect, indicator of reliability. While "expensive guideline = good guideline" is by no means the rule, guidelines promulgated with excessive frugality might raise questions as to their thoroughness. Whether guideline development was totally or partially funded by "industry" should also be considered as potentially influencing the guideline panel's recommendations, as should potential economic windfall to a particular physician group resulting from guideline use. A guideline issued by one medical specialty society in reaction to one issued by another (for instance, in the context of a potential "turf battle") is additional cause for increased scrutiny on the part of the reader/user. The credentials, reputations, geographic locations, and practices of those experts utilized in guideline formation should be assessed. The presence on a guideline development panel of "prominent" physician academicians and administrators should be counterbalanced by the presence of "end user" practitioners. If one panel component is over-represented, the scope of the guideline actually produced may be narrower than that originally intended. Guideline development through "multidisciplinary, collaborative efforts spanning large areas of expertise" is preferable. Further sources of bias in guideline design and promulgation may exist and should be considered in soundness evaluation. Guidelines of sufficient complexity as to risk circularity or other logical inconsistency should be parsed for these occurrences as has been described for an artificial intelligence domain model for ICU monitoring. Finally, if the guideline has been field tested prior to its issuance or reissuance, the results of such should be made known to the potential user. This is particularly true for those guidelines for whom randomized controlled trials are lacking as basis for treatment recommendations. Such consensus-based "gray area" guidelines are analogous to experience-based individual clinical "judgement calls" routinely made by clinicians. Rules of the type IF...THEN...ELSE, as would be natural for an DST application, describe only with difficulty this intrinsically imprecise paradigm.

The process undertaken for soundness evaluation of guidelines can also be utilized for evaluating their "derivative" products. Such derivatives might include guidelines issued by local entities in order that those developed nationally
may be “regionalized” to the particular needs of a locality. Translation of a guideline into software could itself be considered such a “derivatization.” The current AMA Directory of Practice Parameters has begun to list those medical specialty society and other guidelines that are judged to meet the AMA criteria for desirable attributes. Explicit outcomes research may be the most effective arbiter or certifier of guidelines, with public disclosure of poor performance being the best antidote to bad guidelines or inappropriate usage.

6. Liability for Users

Guidelines have potential, through common law or legislation, to preempt other evidence in establishing standards of care. This use in the context of a medical malpractice action might raise the specter of strict or per se liability if a physician deviates from a guideline. It is argued that even if true, such is still more desirable than many aspects of the present system of establishing standards. It would certainly be more beneficial to practitioners/defendants to be prospectively cognizant of a standard established by a guideline than to be subject to a standard opined ad hoc by an expert witness. Additionally, practicing clinicians have opportunity, through medical specialty societies and the AMA, to influence the process of guideline development. No such opportunity exists to retrospectively influence the opinions of expert witnesses. Evidentiary uses of guidelines are not limited to the court room. A well-crafted guideline raised during discovery may result in a more expeditious settlement of the action, whether or not the particular jurisdiction has legislated the use of guideline evidence at trial.

Practice guidelines, even absent specific legislation governing their use, in all probability are admissible as “learned treatises” in standard exception to the hearsay rule. However, unlike medical texts which become “authoritative” only with time, practice guidelines have potential to gain this status nearly instantaneously.

A guideline could be utilized to impeach the credibility of an expert; there are perhaps few better ways to do so than by confronting the expert with an outright contradictory guideline issued by an organization to which he, himself, belongs. Alternately, it may be possible for opposing counsel and expert to attempt to impeach the credibility of a guideline. Whether the guideline stands up to the AHCPR or the AMA guidelines for guidelines or whether economics played a major role in its formulation are but two potential avenues of attack.

Little data is available as to the current use and effects of guidelines in medical malpractice litigation. In one 1994 investigation which examined 32 U.S. Court cases, 259 insurer closed claim files, and surveyed 980 attorneys, guidelines were more often utilized as evidence against rather than in support of health care providers. Twenty seven percent of responding attorneys reported having at least one case where a guideline was influential in its resolution. It should be kept in mind that the most important question regarding guidelines as liability reducers was not resolved by this study: That is, how often does physician adherence to practice guidelines result in good care and thereby avert maloccurrence/malpractice in the first place?

7. Liability for Developers

Just as the food-poisoned diner might have a case against both the cook and the cookbook author, so it is hypothesized that liability risk may exist for developers of practice guidelines or their decision support applications. As of 1992, there were no known cases of successfully alleged medical specialty society liability for consequences of guideline promulgation.

In order to successfully prove liability on the part of the guideline developer, an injured patient would need to prove that the practitioner would not have acted in such an injurious manner but for utilizing the guideline. Absent a direct affirmation of this by the involved practitioner, this would be difficult to prove. While practitioners will probably not be able to completely shift the blame by pointing a finger at the guideline promulgator, prudent practice dictates that developers and promulgators should nevertheless assume that they will be held accountable in the future. Under traditional doctrines of negligence, if an entity undertakes the promulgation of a guideline, it
should take measures to promulgate it well. This would likely include a responsibility to timely revise the
guideline.\textsuperscript{19} Should the guideline developer or promulgator be part of a government agency or an outside group
authorized by the government, it may be entitled to governmental immunity.\textsuperscript{43}

While no such cases have as yet been successfully alleged, physicians and other professionals who serve on guideline
expert panels or who incorporate guidelines in design of DSTs should consider the risk of individual liability if the
guideline or application is later implicated in patient harm. Developers might request indemnification by the
spONSORING organization, and/or inquire to their malpractice or other insurers as to whether such activity is covered
under their policies.

In addition to the above liability risks in tort, promulgators of guidelines also face risk of antitrust and restraint of
trade if a guideline specifying a particular clinical decision allegedly unlawfully harms an entity with an economic
interest in an alternate decision. Potential aggrieved entities include manufacturers of pharmaceutical agents or
medical devices whose products have been "unfairly" slighted pursuant to a specified decision.\textsuperscript{24,44}

8. Legislation, Regulation, and Public Policy

Legislative eagerness in pursuing utilization of guidelines at times parallels that of medical specialty societies in
generating them. The U.S. federal government and approximately a dozen of its states have pending or enacted
guidelines legislation.

States have utilized different approaches in pursuit of guidelines legislation. Maryland law\textsuperscript{45} requires greater than
60\% of specialists affected by a guideline to first approve it prior to its adoption (compared with Maine's 50\%
threshold\textsuperscript{46}). States differ as to whether a guideline may be introduced with equal ease in medical malpractice trials
by either plaintiff or defense. Different legislatures confer upon guidelines different amounts of evidentiary weight.
Such weighting runs the gamut from presumption of nonmalfeasance rebuttable by a preponderance of evidence (as
proposed in NY\textsuperscript{47}) or by clear and convincing evidence (proposal before U.S. Senate\textsuperscript{48}), to per se immunity\textsuperscript{40} and
"absolute defense" as is law in Minnesota.\textsuperscript{49}

Utah's proposed legislation decreed that all guidelines utilized pursuant to it would remain in the public domain.\textsuperscript{50}
With limited exceptions, medical treatments and procedures are generally held not to be patentable.\textsuperscript{51,52} Medical
computer applications and software, however, are subject to patent and copyright pursuant to a large body of
constantly evolving intellectual property law.\textsuperscript{53,54} What will ultimately be the predominate intellectual property
paradigm for guidelines-based expert systems and other DSTs in medicine is speculative.

9. Conclusion

Present and future uses of practice guidelines in health care delivery run a gamut of medical and legal concerns of
which both users and developers must be cognizant. The threshold between guideline and standard is often unclear
but has recently received definition in the legislation of several states.

Physicians and medical educators should support efforts to validate individual guidelines and strengthen the role of
"science" in guideline general development and promulgation. Outcome studies should investigate whether the
theorized fruits of guidelines and of DSTs are actually realized. Medical educators and administrators have a
responsibility to make trainees and staff aware of guidelines pertaining to their practices. Included among these may
be guidelines issued by entities "outside" a practitioner's specialty.

Members of medical specialty societies should know of the guidelines which their societies have issued. While
familiarity with them need not approach that of "Bible study," knowledge of their existence and general substance
would benefit those who may later be alleged to be subject to their contents.
Individuals considering participating in guideline or derivative development should seek indemnification for so doing from the sponsoring organization. This holds true for the creation of guidelines-based DSTs. In addition to this, an inquiry should be made to the participant's liability insurance carriers as to whether such activities are covered or excluded. Medical specialty societies, managed care organizations, and DST developers, vendors, and marketers should take careful steps to minimize individual and corporate liability associated with promulgation of guidelines or their derivatives. Utilizing both experienced legal counsel and physicians knowledgeable in the guidelines process will aid in this endeavor.

References


Table 1: IOM/AHCPR Desirable Attributes of Practice Guidelines

Table 1: IOM/AHCPR Desirable Attributes of Practice Guidelines

Attribute and Explanation

VALIDITY - guidelines:
If followed, will lead to the expected outcomes
Assess the substance and quality of the evidence cited in them, and their means of evaluation
Assess the relationship between the evidence and the recommendations
Include estimates of the health and cost outcomes expected in comparison to alternate practices
Consider patient perceptions and preferences.

RELIABILITY/REPRODUCIBILITY
Given the same evidence and methods, another set of experts would produce essentially the same statements. Given the same clinical circumstances, the guideline is interpreted and applied consistently.

CLINICAL APPLICABILITY
Guidelines should be as inclusive of appropriately defined patient populations as evidence and expert judgment permit, and should explicitly state the population(s) to which they apply.

CLINICAL FLEXIBILITY
Guidelines should identify exceptions to their recommendations and discuss how patient preferences are to be identified and considered.

CLARITY
Guidelines must contain unambiguous language, precisely defined terms, and utilize logical and easy-to-follow modes of presentation.

MULTIDISCIPLINARY PROCESS
Guideline development must include participation by representatives of key affected groups. Participation may include serving on panels that develop guidelines, providing evidence and viewpoints to the panels, and reviewing draft guidelines.

SCHEDULED REVIEW
Guidelines must include plans for review to determine whether revisions are warranted, given new clinical evidence or professional consensus.

DOCUMENTATION
The procedures, participants, evidence, assumptions, rationales, and analytic methods all employed in guideline development must be meticulously documented and described.
Table 2: AMA Desirable Attributes of Practice Parameters

General Characteristics

1. Development by physician organizations or in conjunction with them:
   Inclusion of requisite medical expertise and broad based input of practitioners likely to be affected. If parameters “cross lines of disciplines or specialties,” appropriate specialties should each be represented.

2. Use of reliable methodologies that integrate research findings and appropriate clinical expertise:
   The process of literature review is described. Included or available on request are:
   - The evidence reviewed, the clinical review process and specialty affiliations and credentials of the reviewers, statements regarding the basis (scientific literature vs clinical judgment) for the parameter.

3. Practice parameters should be as comprehensive and specific as possible:
   Parameters should note indications for appropriate management in specific clinical situations.

4. Practice parameters should be based on current information:
   Provision is made for periodic review. Date of completion/publication is specified. Initial writing, review, or revision has occurred within the last 3 years.

5. Practice parameters should be widely disseminated:
   Provisions are made for sources where the parameter will be available and noted, and mechanisms for distribution are identified.
The Development of a Research Database to enhance Autonomy and Evidence-based Practice in Public Health: The Public Health Effectiveness Project

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Key words: Public health, database, evidence-based practice, dissemination

Abstract

BACKGROUND: Public Health workers are increasingly looking to research for guidance in making clinical decisions, advocating for programs in a competitive health care environment. However, finding and retrieving available information is often difficult and time-consuming.

OBJECTIVES: This paper describes the development, maintenance, and dissemination methods of a user-friendly, computerized reference database of public health research literature. Primary goals of the database are to facilitate the production of systematic overviews and support evidence-based practice and decision-making.

METHODS: A series of systematic searches for published and unpublished literature yielded over 3000 relevant articles which have been entered into the database. The literature includes primarily intervention studies with some background articles. A system of keywords related to public health interventions was developed and applied to every entry. This keywording system allows users to conduct searches and retrieve studies according to clinical topic, research design and quality, study population, intervention strategy, and outcome category. Background articles can also be searched by research methodology, outcome measurement, public health practice and management, and health care policy.

DISSEMINATION: The database has been disseminated through presentations in local, national and international venues, newsletters and online services. Various methods to evaluate online site use are being developed.

RESULTS: 40-50 requests are received and responded to annually from public health workers, managers, health organizations, and other researchers. The database provides the literature management system for ongoing production of effectiveness overviews (7 completed).

CONCLUSIONS: Three years of search, retrieval and keywording of public health studies has resulted in a user-friendly resource of effectiveness research accessible to decision-makers in practice and policy. The number of requests received demonstrates the potential of the database to facilitate evidence-based practice. Further development and evaluation of dissemination and coordination methods is required.

1.0 Development of the Public Health Database

The Public Health Effectiveness Project is a research endeavor that started in July of 1992, consisting of a project team that includes the primary researcher, consultants to the health unit and a former public health nurse acting as project coordinator. The objective of the project is to draw conclusions about the effectiveness of selected public health interventions and offer recommendations for practice to policy makers, program planners and public health providers by utilizing a systematic overview approach. This requires the accumulation of a vast amount of literature that must be organized and easily accessible. A second objective of this project was to make the database available to health department staff and managers throughout Ontario, so as to facilitate evidence-based practice from current evaluation research studies. The database is maintained both in hard copy format and as an electronic database.
Reference Manager is the database software package used by the Public Health Effectiveness Project. Reference Manager can be customized to suit individual data and informational needs. This research project has customized Reference Manager to develop a database specifically for producing systematic overviews of Public Health intervention effectiveness. Reference Manager allows storage, search and retrieval of information on each article entered into the database.

2.0 Maintenance of the Public Health Database

2.1 Search Strategies

The search capabilities of Reference Manager are extensive. Reference lists can be generated by searching for author names, titles, keywords, reference identification number, year of publication, type of article, to name a few.

Currently, over 3,000 articles have been entered and keyworded on Reference Manager. As each article is entered it is assigned an identification number. Each hard copy of the article is labeled with this identification number and filed in numeric order. The search strategies used to retrieve articles for the database include MEDLINE, CINAHL, and PSYCHLIT database searches back to 1979. As well, the reference lists of each article are checked for potentially relevant titles. Unpublished works are retrieved through key informant discussions, and liaison with public health researchers across Canada.

The types of articles retrieved for the database include evaluation studies of interventions within the scope of public health nursing practice within Canada. Approximately 70% of these evaluation studies are related to the areas of home visiting, community development, adolescent suicide prevention, parent-child health, and community-based interventions. Articles that simply describe interventions or study prevalence rates of an issue are generally not retrieved for entry. Fifty percent of the database consists of background articles such as evaluation research methods, overview methods, discussions on how to measure outcomes, defining interventions, public health practice / management issues, and health care policy. It must be noted that most studies involve several populations, interventions and / or outcomes at one time. Therefore, each category is not mutually exclusive and the percentages will add up to more than 100.

2.2 Keywording / Relevance and Validity Testing

The most distinguishing aspect of the database is the public health specific keywording tool. A keywording tool was developed, pretested and applied to every article entered into the database. This has facilitated the retrieval of articles for specific systematic overview topics, as well as provided a user-friendly resource for public health staff in Ontario and Canada. The keywording tool categorizes information into specific sections. The categories most relevant to public health include:

- County research originated from
- Clinical topic
- Type of article (evaluation, descriptive, review article)
- Article category (intervention, background)
- Research design
- Research methods
- Study population
- Intervention provider
- Intervention location
- Intervention service
- Program process outcomes
- Behaviour outcomes
- Physical / mental / social outcomes

Articles can be retrieved from individual categories if a broad search is needed, or for more specific searches several keywording categories can be connected. For example, a search could look at all the articles on file that have a clinical topic of injury prevention, or incorporate more parameters such as a target population and intervention...
service. This search would then retrieve only those articles on injury prevention that also looked at the specified
target population and type of intervention. Articles are also keyworded for two additional attributes: whether they
passed relevance testing for a particular overview topic; and the validity rating assigned by project team members
regarding rigor of the research methods used. Therefore it is possible to search for articles on interventions that have
been rated as being of strong methodological quality. The proceeding on the Public Health Effectiveness Project
describes relevance and validity testing in more detail.

2.3 Storing of articles in hard copy

After each article has been reviewed for keywords, entered on Reference Manager, and assigned an identification
number, the hard copy is filed numerically. Attempting to file articles according to topics and target population lead
to difficulties in retrieval, since many studies cross population and topic boundaries. A standard tool that clearly
categorizes relevant information that can be retrieved by searching for specific keywords eliminates the need for
filing by topics, and facilitates an efficient, quick retrieval process.

Another key factor in maintaining an up to date database in hard copy, is to keep all original copies in file at all
times. Allowing the original copies of articles to be removed from the office can lead to the loss of that article and
having to retrieve it a second time. It is also necessary to have all articles in the database available in hard copy, in
order to promptly reply to the many Reference Manager requests by staff and managers for specific articles.

3.0 Dissemination Methods and Results

One of the objectives of the Public Health Effectiveness Project is to utilize a systematic overview approach to
develop recommendations for practice and to disseminate these findings to practitioners, managers, program planners,
and policy makers throughout Ontario to facilitate evidence-based practice at all levels of intervention. To date,
several requests from public health staff, managers, and researchers in around the world. Over the past 4 years,
requests have increased each year from ten to fifty. Requests can be made in any of the following ways: by writing to
the Public Health Effectiveness Project at PO Box 897, Hamilton, Ontario, Canada L8N 3P6; or by calling / emailing
the project coordinator at (905) 546-3532 / gbrunton@hwdp.hamilton.on.ca

4.0 Conclusion

The Public Health Effectiveness Project team members have presented the database at local, national and
international venues, in provincial newsletters and via Internet services. Future plans include evaluation and further
development of online dissemination. These dissemination methods have so far resulted in requests from public
health practitioners and policy decision makers for articles on specific public health topics. In addition, the PH
database is used as the literature management system for ongoing production of systematic overviews of effective
public health interventions. The database is now the first searched in a retrieval of articles for a relevant overview,
and any additional articles retrieved for that overview are then keyworded, relevance tested, quality rated if relevant,
and put into the PH database.
Casemix Simulation Modeling in the Health Care Industry

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Keywords: Casemix, Simulation, System Dynamics Model, ithink, Strategic Decision Support

Abstract

In recent years, there has been an increase in the use of casemix as one of the main elements for determining the allocation of resources to individual hospitals. Although private hospitals operate on thin profit margins, the application of DRG-based case weights to determine the cost of hospital services is still heavily influenced by the experience of the Australian Commonwealth government's payment scheme for Medicare beneficiaries as a primary source of hospital funding besides private health insurance.

In this paper, we have conceptualised a visual interactive simulation model using casemix funding as the basis for the relationships between the GP referrals, the admitting rights of Specialists, DRG cost weights, hospital service and facility capacity, capital debt servicing and the financial position of the hospital. Further, we have extended this model to incorporate multiple DRG’s.

A characteristic of the casemix model is that it may be designed to replace much cruder measures in financial transactions, such as the use of unadjusted bed-days. In Australia, the Medicare Agreements between the Commonwealth government and the States provide for a reduction in Commonwealth funding if the ratio of casemix weighted public patient bed-days to total weighted acute hospital bed-days falls below a predetermined level.

Simulation studies using this Visual Interactive model shows the need to address the financial impact of the use of alternative payment rates by DRG, and the implications of Specialist succession policies for the hospital, the demand for specific hospital services and the hospital services that should be outsourced. It is also able to allow the user to make informed strategic decisions on the expansion or substitution of hospital services according to the seasonality of the demand and the effects of operationalising preferred actions. Sensitivity analysis can be performed to test the accuracy of cost weights.

This generic model is a significant contribution to casemix management and long term strategic management of hospitals. Due to its ease of use, it will enable hospital planner and administrators understand the fundamental business processes.

Introduction

All patients are unique and it is fundamental to good patient care that they be treated as individuals. However, it is useful to classify, or to recognise that there are similarities between groups of patients. Indeed, health care professionals have always classified patients and their episodes of care such as surgical, psychiatric, high dependency, post operative, and so on. It is necessary to state that patient classifications can help to determine outcome, quality, or cost of care.
Use of Casemix Data and Market Segmentation by DRG

A casemix classification differs from other classifications because of its:
- clinical meaning (patients in the same class should have clinical similarities),
- resource use (patients in the same class should cost roughly the same to treat) [Eager K & Hindle D, 1994].

Market segmentation is a managerial concept used to identify consumers or firms likely to use or buy services. So, for example, some plausible dimensions used to segment the market for hospital services include the admitting specialist, the clinical specialties, and the usual demographic and socioeconomic attributes (eg age, sex, and income). Many hospitals define markets in terms of clinical specialties. They determine geographic market share by clinical specialty (eg. cardiology, general surgery, oncology, orthopedics, ENT) and predict future trends. For example, the cardiology market needs to support its service with the provision electrocardiograms, cardiac surgery, stress tests, cardiac catheterization laboratories, cardiac rehabilitation and so on. So, in a sense, narrow clinical speciality can be considered a DRG.

In this paper and the subsequent simulation model developed we have used the casemix classification known as the Australian National Diagnosis Related Groups (AN-DRGs) Version 3 which consists of 527 classes of acute inpatient episodes. Without debating further the different interpretations that can be attributed by clinicians to different casemix classifications, we assume that Version 3 has evolved from previous versions and thus become more acceptable to clinicians [Palmer G.R.,1990].

The private hospital market is driven by primarily by consumer choice, preference for a better quality product and on a 'user pays' basis. So, the natural question to ask is "Which emerging markets will offer private hospitals the greatest growth opportunity?" In the 1980's, hospital chief executive officers (CEO's) became aware of the need for strategic marketing plans. Although, dozens of markets have been targeted and sought after, there is one group of customers that has not effectively been singled out - the customer market for efficient care.

It is hypothesized that this market wants not only quality hospital care, but also physicians (specialists) who can provide the quick route to health. These are specialists whose clinical experience and judgement reduce the amount of unnecessary tests, drugs, and length of stay in hospital. The market for efficient care is a segment that may offer hospitals the greatest single opportunity for differentiation in the future. Therefore, hospitals that can identify and market their best practicing providers will achieve a competitive advantage.

Thus, evaluating best practices in hospitals is an exciting opportunity as it will provide:
- a better understanding of the variations in specialists practice
- better information about specialist practices by analysing medical records rather than health insurance claim files
- patterns and links between casemix and financial data that can be studied across a range of specialists by AN-DRG's

Some hospitals have resorted to offering financial incentives for each patient admission. A few years ago, in an interview in The Wall Street Journal, a specialist who supported these dubious marketing practices offered a possible explanation:
"I can admit to any hospital I want for any reason I want. I don't have to justify that to anybody.... I can admit because I prefer the colour of the carpet or my parking spot at a hospital"

This quote implies that the specialist with admitting privileges at several hospitals and has no contractual obligations to choose one from the other. There is no evidence that this attitude is widespread but it shows the importance of the a responsible hospital-specialists alliance [Chiligerian, JA, 1992].

In fact, in the Australian context, it is possible for hospitals to extend this alliance to the General Practitioners (GP's), being the next link in the Medicare system with the formation of medical clinics. Backward integration into the supply chain for patients provides a unique mechanism for capturing of market share.

In the Commonwealth Medicare Benefit Scheme (CMBS), private patients are defined as those with private health insurance cover. Under Medicare, the CMBS pays 75% of the scheduled fee as determined by the Government. The
private health insurance companies will bear an additional 10% (ie up to 85% for each CMBS number) with exclusions, excess etc depending on insurance policy liens and type. The balance of the payment depending on the specialist’s fee for the procedure (CMBS number) will have to be borne by the patient. Operating theatre fees and hospital bed fees generally tend to be paid by private health insurers with some variations. We have limited the simulation model to the admission of patients by specialists and others such inter-hospital transfers, emergency admissions are excluded from this study.

System Dynamics Modeling and Model Description

System dynamics is the application of feedback control systems, principles and techniques to managerial, organisational and socioeconomic problems. The approach may be traced to the control engineering as a systematic methodology for the analysis of information feedback systems. The application of feedback control systems to management-related applications originated with Forrester at the MIT Sloan School of Management.

In the system dynamics approach, planning problems can be represented in casual flow diagrams that depict organisational relationships as a sequence of reservoirs and flow regulators. Levels in the reservoirs represent accumulation of resources such revenue, patients admitted, the private market for a particular DRG etc. Flow regulators include activities within a system such as flows of effort, cost of care, arrival of patients by DRG, admissions and separation rates. We have identified two major loops in this study, a reinforcing loop (+ve) and a balancing loop (-ve) as shown above. The simulation approach can involve entirely endogenous, non-linear causation within a dynamic framework. The model based on the system dynamics paradigm has been built to demonstrate the applicability of casemix and financial principles to the management and allocation of resources in a private hospital.

In the review of the system dynamics framework, Wolstenholme (1982) emphasised the distinction between qualitative and quantitative analysis. He claimed that this distinction was the most important for analysis of 'soft' systems which involve at least some hard to measure relationships or may involve a purely qualitative pattern of causality. The descriptive or qualitative modeling phase could "...particularly in the case of very soft systems..." be considered "...as an end in itself or a forerunner to simulation analysis." [Wolstenhome 1982,].

In applying these concepts to the process of model building developed from a dynamic hypothesis of SJOG Murdoch Hospital in the casual loop diagram above, we have attempted to model the specialist quality of work and the patients' perceived reputation of the particular specialist as one of the driving factor which determines the choice of specialist. Furthermore, market research shows the patient's choice of a specialist for admission to hospitals is primarily determined by the following factors the:

- gap in consultation fees to be borne by patient for each treatment needed (CMBS number) for that episode,
- cost and waiting time for the first and subsequent consultations (not covered by

Fig 1: Casual Loop Diagrams for SJOG Murdoch Hospital
private health cover but 85% covered by Medicare)
- gap in hospitalisation and theatre fees for hospital used by the specialist
- proximity of the hospital

The simulation model we have developed uses the above criteria for admission of patients.

The powerful mapping, modelling and simulation capabilities of ithink can transform the exercise in linear extrapolation into a powerful learning experience that captures the dynamic complexity of the health care market. An understanding of complexity, in turn yields results that can shift an organisation's perspective, altering the timing and intensity of its strategic actions.

We began by formulating a high level map of a dynamic ithink-based model that defined the relationships among forecasted variables. The mapping involved the following:

- **Market Segmentation Frame** - identification of the total market, total private market and the St John of God Hospital (SJOG) Murdoch market share for each AN-DRG, yielding the aggregate demand for hospital admissions through specialists only as bounds with time based frequency of admissions representative of forecasted demand.

- **Medical Center Process Frame** - patient admissions are allocated by specialists (physicians) with admitting privileges to several hospitals - the patients' preference for the specialist can be simulated by adding relative weights of importance to the consultation gap, hospital bill gap, health insurance cover restrictions, waiting time for consults prior to admission, perceived reputation of the specialist in the marketplace. Alternatively, the choice of the specialists to use the hospital facilities can also be simulated by the use of hospital target setting range of values for each of the above decision criteria.
**Cashflow & Diagnosis Related Group Process Frame** - the simulation of cost weights for each DRG, length of hospital stay based on patients' age, mix of investigations and treatment procedures based on the CMBS/DRG map and theatre fees [Wiley M.M., 1992]. The patient payor and health insurance company's components of hospital revenue are included in the process frame. A further minor but significant frame is the capital debt servicing frame - where revenue gains are channelled to service the principal and interest due for each financial period.

**Key Model Assumptions and Sensitivity Analysis**

Any mental representation is as useful as the assumptions made. The model is driven by a standard cost weight for each DRG so that assumes staff cost as an average. The fact that hospital beds are interchangeable between DRG's is hypothetical but it can be redefined when multiple DRG's are introduced. Ward classifications have not been considered. Many of the hospitals' auxiliary services provided has been aggregated. We have not considered the differences between the various private health insurance companies. The CMBS/DRG map is not precise in its relationship but is used to forecast the expected treatment procedures for each episode. The validity of the model has been tested against the trends of casemix data provided by the St John of God Murdoch hospital and we have extrapolated behaviour patterns and consistent with historical trends.

The model can be used to decide the effects of some major strategic issues such as:

- expansion of bed capacity for the hospital and the timing of the expansion just-in-time to coincide with demand. This has other implications for the planning and recruitment of additional human resources to meet that demand. The forecasted seasonality in demand of the output behaviour patterns will be more reliable if there is consistency and similarity over several years

- selection of specialists who will make best use of hospital facilities and prepare succession plans for retiring specialists or specialists who leave for other reasons

- simulating the effects of government policy changes to the funding and pricing mechanisms of hospital services through the Medicare System and the private health insurance companies

- testing the private market's reaction and revenue of the hospital to the sensitivity of various parameters such as increased length of stay, growth rates, increase patient payors component of hospital bills and increased competition from other health care providers.

**Conclusion**

Planning for survivability in hospital systems must be approached from a holistic perspective. The dimensions of planning process will extend to clinical, economic and sociological interactions as the private market becomes an increasingly competitive environment. The large volume of casemix data available can be put to good use to generate test case scenarios for the future. However, hospital policymakers must be wary that such simulation models can, at best, be described as tools for decision support which will help strengthen their arguments in the boardroom.

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Public Education Approaches

Chair: Larry Scott
Automatic Customization of Health-Education Brochures for Individual Patients

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Keywords: health education, customization, tailoring

Abstract

Many studies have shown that health-education messages and patient instructions are more effective when closely tailored to the particular condition and characteristics of the individual recipient. But in situations where many factors interact—for example, in explaining the pros and cons of hormone replacement therapy—the number of different combinations is far too large for a set of appropriately tailored messages to be produced in advance.

The HealthDoc project is presently developing linguistic techniques for producing, on demand, health-education and patient-information brochures that are customized to the medical and personal characteristics of an individual patient.

For each topic, HealthDoc requires a master document written by an expert on the subject with the help of a program called an authoring tool. The writer decides upon the basic elements of the text—clauses and sentences—and the patient conditions under which each element should be included in the output. The program assists the writer in building correctly structured master-document fragments and annotating them with the relationships and conditions for inclusion.

When a clinician wishes to give a patient a particular brochure from HealthDoc, she will select it from a menu and specify the name of the patient. HealthDoc will use information from the patient’s on-line medical record to then create and print a version of the document appropriate to that patient, by selecting the appropriate pieces of material and then performing the necessary linguistic operations to combine them into a single, coherent text.

1.0 Customizing health-education documents

Health-education and patient-information brochures and leaflets are often limited in their effectiveness by the need to address them to a wide audience. What is generally produced is either a minimal, generic document that contains only the information relevant to everyone, or a maximal document that tries to provide all the information that might be relevant to someone (and hence much that is irrelevant to many). But documents that contain irrelevant information, or omit relevant information, or that for any other reason just don’t seem to be addressed to the particular reader, are likely to be discounted or ignored. Recognizing this, health educators have paid much attention to methods of identifying different segments of their audience and their differing needs and constructing material accordingly [1]. But the documents remain, to a significant degree, generic.

However, recent experiments (see below) have shown that health-education documents can be much more effective if they are customized for individual readers in accordance with their medical conditions, demographic variables, personality profile, or other relevant factors. This kind of customization involves much more than just producing each brochure or leaflet in half a dozen different versions for different audiences. Rather, given the number of independent variables and their range, the number of different combinations of factors can easily be in the tens or hundreds of thousands. Thus, each brochure must be produced individually for each recipient.
For example, Strecher and colleagues sent unsolicited leaflets to patients of family practices on topics such as giving up smoking [2], improving dietary behaviour [3], or having a mammogram [4]. Each leaflet was 'tailored' to the recipient by a program that selected fragments of text for inclusion on the basis of answers that the recipient had given in an earlier telephone survey. In each study, the tailored leaflets had a significantly greater effect on the patients' behaviour than 'generic' leaflets had upon patients in a control group.

In these studies, the leaflets to be tailored were represented on-line simply as a large set of simple fragments of text to be included when appropriate in both content and form. While this is straightforward in principle, it requires that an extremely large number of bits and pieces of text be available: each fact expressed in each possible way. Sarah Kobrin reports (p.c.) that in extensions to the work of [2], the creation and management of the large number of text fragments involved became extremely difficult. And the assembly of such bits and pieces suffers from the problem that the resulting document might not be coherent or cohesive, or at the very least, not stylistically polished. These kinds of deleterious effects usually become apparent only over stretches of 100-200 words or more, so lack of space precludes us from giving complete examples. But we can show a simplified case. Suppose that the following two fragments are possible components of a text:

*People with respiratory disorders* have a high risk of developing Glaumann's syndrome.
*People with respiratory disorders* should take immediate action to quit smoking.

If in some document these fragments are both selected to appear, and they do so adjacent to one another, then the result is linguistically clumsy; the italicized noun phrase should be replaced by the pronoun *they* in whichever one comes second. Moreover, if the two facts have a causal relationship and appear in the order shown above, then inserting the word *therefore* at the start of the second sentence, rather than leaving the relationship implicit, would improve clarity.

It might be objected that the fragments could be carefully constructed so that all possible selections resulted in a well-formed document. Indeed, Strecher and colleagues attempted just that. However, they found it difficult even for their fairly simple documents (Sarah Kobrin and Victor Strecher, p.c.); it would surely be very hard to achieve for complex documents unless the granularity were extremely coarse, thereby increasing the number of distinct elements required. In the limit, one would simply have a distinct document pre-written for every single combination of possibilities, a situation that would be quite impractical.

Rather, what is needed is a system for the production of tailored health-education and patient-education documents, that would, on demand, customize a 'master document' to the needs of a particular individual. The HealthDoc project is building such a system.

2.0 The conceptual framework of the HealthDoc project

The HealthDoc project aims to develop techniques for producing health-information and patient-education documents that are customized to the personal and medical characteristics of the individual patient receiving it. Information from an on-line medical record or from the clinician will be used as the basis for deciding how best to fit the document to the patient. The project is concentrating on the production of printed materials; brochures and leaflets that the patient can take away to read and refer to whenever they wish. Nonetheless, many of the techniques that we are developing will also be applicable in the interactive, hypertext-like systems that others are developing [5,6].

2.1 The HealthDoc model of patient education

**Master documents:** Each customized brochure is produced from a *master document* on a particular topic. These master documents are created by a medical writer with the aid of an authoring tool. Each contains all the information, including illustrations, that might be included in any individual version, along with annotations as to the conditions under which each piece of information is relevant.
**Dimensions of customization:** A master document may be customized with data about the individual patient, and the selection of content and manner of expression of that content may be determined by the patient's medical condition and their personal and cultural characteristics. Selection may occur at the level of paragraphs, sentences, phrases, or words.

**Clinical use:** In clinical use, HealthDoc would have access to the on-line medical records of patients. When the clinician wishes to give a patient a particular brochure from HealthDoc, she selects it from a menu of master documents, and specifies the name of the patient. HealthDoc will then generate a version of the document appropriate to that patient (possibly asking the clinician for information to supplement that which it finds in the patient's record). The document will be attractively laid out and formatted, and may be run off on pre-printed stationery.

### 2.2 Goals of the present project

The creation of a complete system as just described is beyond the scope and resources of the current HealthDoc research project. The project is at present concentrating primarily on the central research problems in computational linguistics that are entailed by the development of such a system, and in particular the nature of master documents, tools for authoring them, and the generation of coherent text from them.

Both the authoring tools and the processes that refine the selections from the master document are necessarily language-dependent, so at present HealthDoc is limited to English, our working language. We hope that in the long term it will be possible to add master documents in other languages for which the necessary grammars and lexicons are available. (Unfortunately, there are few or no resources available for the languages—Chinese, Vietnamese, Khmer—that are the greatest problems for the hospitals with which we are collaborating.

### 2.3 Customizing patient-education material

A HealthDoc brochure may be customized with data about the individual patient, and the selection of content and manner of expression of that content may be determined by the patient’s medical condition and (in later stages of the project) their personal and cultural characteristics.

**Patient data:** The simplest kind of customization is inclusion of simple numerical or alphabetic data from the patient's chart—in effect, filling in the blanks in a template. This might include the name of the patient, their physician, or details of a prescription. Template-filling is straightforward, and independent of other kinds of customization. Where we speak below about customization by the creation or inclusion of pieces of text, it is to be understood that these pieces might actually be templates that are then further customized by filling with the appropriate data.

**Patient's medical condition and physical characteristics:** Customization by medical condition and physical characteristics entails choosing what to say and not say in the document, in accordance with the patient’s diagnosis, physical characteristics (such as age and gender), and medical history. When several medical conditions interact, the choice of what to include and exclude may be quite complex. For example, the customization of a brochure advising a patient on the benefits and risks of hormone-replacement therapy needs to take into account a large number of interacting factors in her medical history and that of her family. It is in such cases that customizable documents will be of particular utility.

**Patient's culture, health beliefs, and other personal characteristics:** Customization by patient characteristics involves the choice of both form and content. Many studies have shown that the 'same' message often needs to be framed or presented in very different ways in order to be communicated most effectively and most persuasively to different people; individual and cultural differences in health beliefs, perception of and attitude to risk, and level of education are among the factors that must be considered when tailoring a health message to an individual [1,7]. Indeed, what may be persuasive to one person can actually reduce compliance in another [8]. Despite its restriction to a single language, the later phases of the HealthDoc project will attempt to customize documents to account for cultural differences in health beliefs and other individual differences.
Customization or tailoring thus involves much more than the mere inclusion of data about the individual patient. For example, giving a patient a textual summary of their chart would not, by itself, be tailoring, even though the information is particular to that patient. But if the creation of the summary were to take into account how the information is best presented to that individual, or if the information in the chart were used in deciding the form or content of a different health message, then tailoring would have occurred. HealthDoc is thus distinguished from ‘tailoring’ projects such as [9], in which what is tailored to the individual patient is a clinical decision model for which an explanation is then produced; individual characteristics of the patient affect the content of the explanation only insofar as they are the inputs of the decision model. The explanation itself is created by filling in template slots with information from the patient’s chart and with phrases that describe which nodes in the model proved to be important in making the decision; templates were pre-written for all possible combinations of decisions, as there were not very many.

3.0 The master document

3.1 The master document and generation by selection and repair

As explained above, a master document is a specification of all the information that might be included in a brochure on a particular topic, along with annotations indicating what is to be included when. We now discuss the nature of this master document and the problems of combining selections from it.

In the simplest kind of customization for content and form, a master document would just be a large set of simple blocks of text (or templates for patient data) as used by Strecher and colleagues; we saw the limitations of this approach in section 1 above. At the other end of the spectrum, the elements of the master document would be pieces of a language-independent structure in some knowledge-representation formalism, and would be selected for content but not form. These elements would then have to pass through some complete language-generation system that would decide on how to organize and express the content, given information about the form best suited to the patient’s personal characteristics. This approach is elegant and flexible, but is not yet close to being possible for domains as complex as those of interest here.

Our approach is a workable compromise between these extremes. The master document is represented neither in a knowledge-representation formalism nor as text blocks, but in an abstract text specification language that expresses not only the content of the document but also information that will assist any subsequent process of revision; this language will be described below. Selections from this document are made for both content and form, and are then automatically post-edited—"repaired"—for form, style, and coherence. These repairs take place upon the abstract representation, and are guided by the additional information that it contains.

Thus in this process of generation by selection and repair, the starting point is a partially specified, pre-existing document with an overall text organization, division of propositional content into sentences, choice of words, and lexical cohesive structure. Even though the system might subsequently modify many of these aspects as it produces a customized text from the master document, we nonetheless start from a highly useful draft form, rich in linguistic and stylistic information—in effect, we observe the maxim that it is generally much easier to re-write than to write. We discuss generation by selection and repair at greater length in [10].

3.2 Text Specification Language

Text Specification Language (TSL) is a language that we have developed for the internal representation of master documents. It is an extension of the Sentence Plan Language (SPL) used by the text generation system that HealthDoc employs for realization of its final output [11]. TSL expresses the content of the document, and permits this content to be annotated as to which elements are to be selected from the master document under what circumstances.
Annotations for selection may refer to the patient’s medical record or to information that the clinician could supply, such as the patient’s reading level or the preferred style of presentation. For example:

- patient-age (greater-than 70)
- patient-blood-pressure (high)
- patient-recent-medical-history (myocardial-infarction)
- patient-history-reliability (good)
- reading-level (fourth-grade)
- formality (low)

These must be translated to queries on the medical record or to the clinician. Note that “don’t know” is a possible answer that the author of the master document must allow for.

TSL also includes two kinds of information to guide ‘repairs’ to the selected text: coreference links and rhetorical relations between sentences. Each object or entity referred to in any fragment of the document is represented by a pointer into a list of all objects referred to, along with the kind of reference: definite or indefinite, extensional or intensional, and so on. Thus, it will always be known if two different sentences refer to the same thing, and pronominalization can occur accordingly, as in the example in section 1. Rhetorical relations are cohesive relationships between sentences such as CAUSE, CONTRAST, ELABORATION, and so on. All such relationships between sentences in the document are recorded in the TSL, so that markers such as therefore and however can be used in the text where appropriate, again as in section 1.

For example, the following is the TSL structure for the sentence “The condition that you have is insulin-dependent diabetes”. Comments are indicated by a ‘%’ sign.

```
:tsl
  '(asc / ascription
   % Annotations for selection:
   :patient-diagnosis (insulin-dependent)
   :technicality (all)
   % Information on context:
   % "diabetes" was the focus of the preceding text
   :focus diab6
   % Content of sentence:
   :tense present
   :domain
   (cond / abstraction
    :specific cond0
    % coreference link to other instances of "condition"
    :lex condition
    :determiner the
    :process (have / ownership
     :lex have-possession
     :tense present
     :domain (hearer / person)
     :range cond))
   :range
   (diab6 / abstraction
    :specific diab4
    % coreference link to other instances of "diabetes"
    :lex diabetes
    :determiner zero
    :property-ascription
    (ins / quality
     :lex insulin-dependent))))
```
3.3 Authoring a master document

The author of a master document would normally be a professional medical writer, who will need to understand the nature of customized and customizable texts but who is not assumed to have any special knowledge or understanding of TSL or the innards of HealthDoc. The authoring tool, presently under development, must therefore be no more difficult for the author to use than, say, the more-sophisticated features of a typical word processor. The text is therefore written in English, and translated to TSL by the authoring tool. (The English source text is also retained for use in subsequent sessions, for example, if the document is to be updated or amended.)

It is the writer's job to decide upon the basic elements of the text, the rhetorical and coreferential links between them, and the conditions under which each element should be included in the output. The elements of the text are then typed into the authoring tool in English, and are marked up by the writer with conditions for inclusion and with links for cohesion and coreference. The tool will then translate the text into TSL. This is essentially a process of parsing, but the resultant structures are (annotated) TSL expressions rather than parse trees. Whenever an ambiguity cannot be resolved, the writer is queried in an easy-to-understand form; for example:

When you say "treat the patient with myoform", do you mean
1. the patient with myoform is treated
2. the patient is treated with myoform

4.0 Automatic post-editing

After material in the TSL master document has been selected for a particular patient, textual repairs or post-editing might be needed. The sentence planner in which these mechanisms will operate is presently under development. It uses a blackboard architecture in which individual sentence-repair modules communicate and resolve their conflicts with one another. The architecture is described in greater detail in [12]. Four modules are being built in the first phase of the project: for reference, rhetorical relations, aggregation, and constituent ordering.

Coreference repairs, for example, include decisions as to when a reference should be pronominalized. If the two sentences of the example in section 1 turned up in close proximity, the italicized noun phrases would be recognized as coreferential because in their TSL form they would be labelled with the same referent symbol. The first occurrence would therefore be marked for realization as a full noun phrase, and the second would be marked for pronominalization.

5.0 Realization and formatting

The final specifications for the edited text, represented in SPL, are passed to the realization stage, which uses the KPML text generation system [11] to generate an appropriate surface form in English. A formatter then lays out the text attractively and adds headings and illustrations for final printing.

6.0 Conclusion

The HealthDoc project aims to provide a comprehensive approach to the tailoring of patient-information and health-education materials for the individual patient. The earlier results of Strecher and colleagues [2,3,4], showing the benefits of such customization, justify the importance of what we are doing for a community health-care setting. However, the ability to create customized health communication points out that, while the need for such customization has been long recognized, there has as yet been little research on how information may be conveyed most effectively to individuals with particular characteristics in order to motivate a change in their behaviour. In the next stage of the project, identifying critical examples of variations in text by medical condition and by health beliefs will be an important task.
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References


The Public Health Effectiveness Project: An Overview

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Abstract

Philosophy: The Public Health Effectiveness Project is a group committed to evidence-based practice and policy decision-making. This is achieved by the composition and dissemination of critical and comprehensive overviews evaluating the effectiveness of public health intervention studies. Primary investigators are cross-appointed Clinical Nurse Consultants and staff and administration at the Hamilton-Wentworth Department of Public Health Services, a Teaching Health Unit affiliated with McMaster University and the University of Guelph.

Methods: The mandate is achieved by the systematic retrieval of published and unpublished literature on intervention studies which are within the scope of Ontario Public Health practice. The studies are rated systematically for relevance and validity using previously developed tools. The resulting reports summarize the quality of the evidence, the identification of specific effective approaches, and formulate practice recommendations and recommendations for future research, policy planning and implementation. The project also disseminates the overviews and the database to policy-makers, managers and public health staff via presentations at conferences, workshops and through the Internet.

Results: The implementation of this project has resulted in five to eight yearly presentations at local and international conferences. In addition, 40-50 requests for article searches on the database are completed yearly for policy-makers, program managers and front-line staff.

Conclusions: The project is a utilized means to synthesize and communicate current and comprehensive information on evidence-based practice to policy-makers, program managers and public health professionals. Future innovations will evaluate the most effective methods of dissemination.

1.0 Introduction

The Public Health Effectiveness Project is a joint project of Hamilton-Wentworth Regional Public Health Services Teaching Health Unit, the Association of Nursing Directors and Supervisors of Ontario Official Public Health Agencies, the Community Health Nurse Interest Group of the Registered Nurses' Association of Ontario, and the Quality of Nursing Worklife Research Unit. This project, begun in 1992, was initially funded by the Ontario Ministry of Health, Nursing Innovation fund. Project members include faculty from McMaster University who are cross-appointed with the teaching health unit, as well as teaching health unit consultants, public health managers, and a research coordinator.
2.0 Rationale for the Public Health Effectiveness Project

"Public health practice in Ontario and Canada is being profoundly influenced by increasing financial constraints and the health promotion movement." (Hayward, 1993) The changing priorities of policy makers translate at the point of service delivery into a trend away from interventions that public health nurses have implemented for a long time and have found to be effective. As these changes occur, the roles and competencies of the roles of public health nurses are being called into question. Public health nurses and public health staff in general, are being challenged to defend their central place in an evolving public health service and must do so on the basis of evidence regarding traditional skills and interventions, and their impact. (Hayward, 1993)

"There is a strong move in health care policy to look for evidence about health outcomes to justify services. However, many evaluations of public health practice do not measure health outcomes or do not measure them well. Studies are often driven by the needs of quality assurance and programme planning rather than the need to measure effectiveness. In addition, public health nursing research does not have well-developed explanatory theoretical frameworks upon which to base research design." (Hayward, 1993) The objective then of the Public Health Effectiveness Project was to develop a method, by which evidence of the effectiveness of public health interventions could be summarized, so as to impact on decision making in public health services planning.

3.0 Purpose

Initially, the purpose of the Public Health Effectiveness Project was twofold:

- to conduct comprehensive, systematic overviews of the literature on the effects of public health interventions on the health of individuals, groups, families and communities
- to develop a user-friendly, accessible database of the current, relevant literature in public health

However, a third purpose has recently been added to those mentioned above. The third purpose involves evaluating the dissemination of these systematic overviews and the database, on outcomes such as research utilization and decision making behaviours, by program planners and policy makers in Ontario. This new research endeavor is in the data collection phase at this time.

4.0 Methods

4.1 Systematic Overview Method

The methods used were adapted from those outlined by the Cochrane Collaboration for conducting systematic overviews/meta-analysis. (Sackett, 1994) Adaptations of these methods were necessary so as to more appropriately, and accurately critique and evaluate the current research in public health.

4.2 Search Strategies

The comprehensive search strategy used to collect relevant articles includes:

- On-line MEDLINE and CINAHL searches from 1979 to present. Key words used were "public health nurse" or "community health nurse", and "effectiveness" or "comparative", or "control" or "evaluative" study. As well for specific overviews focused searches using keywords on that particular topic were conducted back to 1985.
- On-line searches for prominent authors in the field were done between 1986 to present.
ITCH ‘96: Public Education Approaches


- Published bibliographies, reports from several health research programs and several government documents were hand-searched for relevant articles. Abstracts were reviewed of workshops and papers presented recently at several conferences. Key informants were contacted in teaching health units in Ontario, university schools of nursing in Canada and through a directory of Canadian nurse researchers, for both published and unpublished papers.

- The Canadian Nurses Foundation Library holdings.

- The content lists of 107 related journals were also reviewed monthly from September 1992 to present.

- Relevant references back to 1980 from each article were identified, retrieved and reviewed.

4.3 Rating Tools

The first year and a half of the project was spent developing, pre-testing, and revising several rating tools that were required for the systematic overview process. These included: relevance, validity, data extraction, and outcome tools. As well, there was a need to develop several different versions of each of these tools in order to facilitate their use with the various systematic overview topics. For example, relevance and validity tools were developed for use with research studies that were of a quantitative design, which were most prevalent in research related to home visiting, maternal-child health, and adolescent suicide. However, it was also necessary to develop relevance and validity criteria that were suited more appropriately to the qualitative/quantitative designs in the community development and community-based literature.

To be included in a systematic overview, an article had to meet all of the relevance criteria. The primary reviewer rated all retrieved articles for a particular overview for relevance, and a secondary reviewer also rated a subset of those articles for relevance. If an inter-rater agreement of kappa = 0.86 was achieved, then it was not deemed necessary for the secondary reader to rate the remaining articles.

Relevant articles were then rated for validity by the primary reader with the same kappa level set for inter-rater agreement with the secondary reader. Some of the validity criteria included: method of allocation, participation rate in the study, controlling for confounders, data collection methods, and percentage lost to follow up. Studies were given a rating for each of these criterion according to a pre-determined guideline, and then given an overall validity rating based on the combined total. Studies were rated as being "strong", "moderate", or "weak". Data extraction and outcome tools were also used to extract data such as target populations, interventions, and the types of outcomes measured. Outcomes were further classified according to program process measures, health risk behaviors, and physical/mental/social health indicators.

5.0 Public Health Effectiveness Project Products

Several background papers and systematic overviews have been completed and are accessible in a variety of ways. The full working copies are available through Hamilton-Wentworth Regional Public Health Department, as well, many of the overviews have been submitted to the Canadian Journal of Public Health for publication, and all of the following overviews can be accessed on Internet at: http://hiru.mcmaster.ca/ohcen/groups/hthu/default.htm


231


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A Community Health Information Model: An Information Management Approach to Information Systems Development

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1. INTRODUCTION

The NSW Community Health Information Development (CHID) Project has provided an information management framework to drive an Australian primary and community health information system development. NSW Health has undertaken an extensive consultation program to develop the Community Health Information Model (CHIM). This data model informs, and will align, projects developing information solutions for the Australian health system, particularly in the ambulatory care sector.

The NSW CHID project, specifically the development of the CHIM, has identified a data structure to inform non-institutional ambulatory information systems development. Firstly, it provides a responsive and reflective view of this service sector's information management requirements. The primary and community health service sector encompasses multiple, disparate services whose information management requirements have been identified in one generic data structure making the CHIM a more robust product than alternative models, where any exist. The CHIM addresses issues of integration with other services as the development of the model proceeded around concepts such as continuity of care. The model also addresses the blind spot of social medicine.

Social medicine is a significant proportion of the work undertaken in the Australian primary and community health services sector. This sector was broadly defined for the CHID Project as services delivered outside of an inpatient or emergency service location. Services range from Aboriginal Health, Youth Services, Health Promotion, Community Development, Family Medicine Programs, Mental Health, Discharge Liaison, Sexual Assault as well as traditional services such as Home Nursing and Early Childhood Clinics.

Close links were also established with public health units, hospitals and intersectoral agencies. The disparity between this range of services initially reinforced the traditional view that information required in one service had little application for another service. It was considered that client demographics were realistically the only common data.

The scope of the CHID project was to review information development for primary and community health services delivering health interventions to people in non-institutional facilities located in the community, irrespective of funding distinctions or models of service delivery. The primary goal was to provide an information solution to public funded community health services that was client-focused. A client-focused information solution would reflect the business functions of this sector, facilitate the analysis of continuity of care, allow for outcome development and analysis, inform casemix or service mix funding decisions, and enhance the development of best practice and benchmarking. An organizational structure was implemented in October 1994 and the process for the project was refined from November 1994. A feasibility analysis was conducted throughout 1995.

This paper will comment on the output of the CHID Project feasibility analysis, particularly the CHIM Strategy. This output will be discussed in terms of benefit to information system development and ambulatory classifications development.
2. KEY CONCEPTS OF THE CHIM

The CHIM is an extremely comprehensive, client-focused data model. At first the information model appears extremely complex as it includes 210 entities, 485 attributes, and 357 relationships between the entities and attributes. Built with a bottom-up approach, extensive consultation included 34 workshops with approximately 400 community health service providers from all identified service types and professional disciplines. The CHIM is accompanied by a data dictionary which defines, and provides examples for, each entity and attribute.

The information/data model consultation program, completed in October 1995, was extended for the development of a 'companion' Community Health Function Model. The purpose of the Function Model was to identify the functions within primary and community health services that generated the data structure. This 'companion' model has facilitated the recommendation of relative priorities of functions within this service sector that will be required to achieve the development of a client-focused relational database.

The CHIM and Community Health Function Model also accounted for a consistent need identified by primary and community health service providers. They required an information solution that would facilitate the production of meaningful reports on the reasons people seek service and also outline the activities of service providers, both direct and indirect. Another focus area was an ability to measure service demand and delivery more accurately thereby facilitating service planning and resource allocation. Such requests related to the constant pressures for productivity savings when efficient and effective service delivery is the order of the day.

Both models have been significantly reviewed by primary and community health service providers. A review of the NSW CHIM was conducted within other States and Territories of Australia. The minimal enhancements suggested by these reviews are mostly related to the differences within State/Territory health system governance and reflect the two-tier Australian government structure.

The CHIM has been developed to accommodate outcome and best practice developments which are currently underway within the Australian health care system. Population of these entities and attributes will occur via a National Codeset Development Work Program. Such a program needs to take account of the significant number of outcome and benchmark development projects being completed in the primary and community health service sector. Primary and community health services outcome research in Australia was initiated in 1994 while policy development for best practice guidelines commenced in 1995.

Core concepts in the CHIM are interrelated and are as follows:
- that recipients of health services are Client and Population Group;
- the primary focus is the Issue that they are experiencing;
- the key operational data is the Activity that is conducted;
- the key supporting resources are Service Provider and Physical Resource;
- the coordinating elements are Plan and Communication; and
- the measure of achievement and effectiveness is the Outcome.

Some of the concepts mentioned above correspond to a single entity in the model, for example, client and service provider. Other concepts are found distributed across several entities, notably activity, issue and plan. Definitions of these terms are outlined to clarify their scope.

Client as a single entity refers to a recipient of assistance from a community health service. A client may be an individual or a group, such as, a family or a therapy group. Client also refers to an organization like a school which acts as an intermediary in the delivery of service to an individual. The information/data model allows for complex relationships between clients and multiple ways in which a client can be identified.

Service Provider is a party that plays a role in the delivery of health services to clients, both from a health and non-health perspective. A service provider must be one of the following sub-types: an External Agency; an Organization Unit (within NSW Health); a Position (within NSW Health); or an Individual (an employee of either NSW Health or External Agency or an Individual Provider).
Issue represents the area of concern for a client or population group. It incorporates the medical diagnosis as well as less formalized behavioral and lifestyle issues. Therefore the scope is broader than purely health related issues and includes general life matters, such as accommodation and financial problems. This scope reflects the holistic philosophy of community health services to a client's situation. There is an Issue Type entity which allows for multiple classification schemes for the future coding of issue. An Issue Status entity incorporates an ability to code the lifecycle of issues from recognition to resolution.

Population Group is a portion of the total community that is defined by selecting certain criteria, usually demographics or issue type or location parameters. These groups are often the focus of health promotion or community development activities.

Activity represents the way that service providers spend their time and the method by which outcomes for clients are achieved. Activity Type is a related entity which allows for a description of categories of activity. This is the most connected entity in the model and relates to Service Activity, Provider Activity, Scheduled Activity, Management Plan Item and Plan Activity.

Plan has two types of entity defined in the model. Management Plan is a specific plan which is formulated for a particular client to address one or more issues with a coordinated method. In contrast, the Plan entity is the main vehicle to support the needs of health promotion and identifies priority areas associated with population groups, defines a time span and specific outcome.

Outcome is a degree of change in the state of well-being of a client or population group. Target and Actual Outcomes are recorded within the context of client management plans and population based plans. Further, a population outcome is often an 'interim outcome' as the real outcome requires an extensive timeframe.

Communication is a record of a communication that occurred between a service provider within a community health services and another party, which may be a client, a client related party (such as a carer) or another service provider. Communication may be incoming, outgoing or internal and occur by telephone, face to face contact, an electronic message or a standard mail item. Communication has a primary purpose, such as, Service Request, Notification, Enquiry, Complaint, Consent or Appointment.

Resource has a major component embedded within Service Provider as expected in a human service. However, there is significant involvement with non-human resources which facilitate services, such as, vehicles, rooms, equipment and information resources. The model recognizes these as Physical Resources and allows for bookings, usage and maintenance records. This resource concept is primarily depicted through a Resource Classification Value which is used to describe the type of resource which may be described in a Management Plan Item or Service Activity Resource or Requisition Item or Invoice Item.

A related Primary and Community Health Services National Information Management (PACHSNIM) Project has identified a similar group of concepts. Of particular interest is the reinforcement of Issue and Activity Type contained in the CHIM. Apart from the scope and level there is only one minor difference between the State and National information models, that is, Activity Type is known nationally as Service Event with a sub-type of Health and Welfare Service Event.

3. BENEFITS OF THE CHIM

The CHIM is currently finding a context in national information management within the Australian primary and community health service sector. The comprehensive, robust and flexible nature of the CHIM has been identified during consultation with other State Health Departments in Australia. A significant level of support for the CHIM, as a tool from which to develop a primary and community health information system, exists nationally. Currently there are three States and one Territory committing a significant level of funding to the development of an information system following a review of the CHIM and it's applicability to their client service operations within the primary and community health sector.
The two concepts identified as extremely important in the CHIM are Issue Type and Activity Type. These two entities are best described as the products of a community health service with Activity Type being the most connected entity within the model. Issue Type and Activity Type reflect the fundamental bases of casemix classification - clinical meaning and resource homogeneity, that is, Issue Type provides indicators of clinical meaning while Activity Type concentrates on measures of resource homogeneity.

The other major benefits of the CHIM to both information, casemix classification and costing systems development, are the potential opportunities available within the primary and community health sector to:

- implement common data standards and coding systems nationally which are capable of international comparison;
- analyze continuity of care across, and within, sectors of the NSW Health system;
- extend ambulatory classifications/codesets and apply them to both government and non-government organizations; develop ambulatory classifications which focus on the social health arena and capture the diversity within 'wellness' service provision;
- to inform, review and validate existing ambulatory casemix classifications as well as those works in progress; identify the interface with existing health information systems;
- provide a tool for information systems users to communicate with information systems developers; and
- reduce the time in specification of the information system.

An information model such as the CHIM provides a generic data structure from which to develop standard codeset descriptors. In terms of codeset development, both the CHID and PACHSNIM Project reflect the importance of issue and activity type within their respective models. This has led to a Feasibility Study into the International Classification of Primary Care - Plus (ICPC+) as an international classification for the primary and community health sector. Initial findings are positive that redevelopment of this schema will meet the coding requirements for issue and activity type. The CHIM is also the basis for prioritizing the standard codeset development required in the information system.

In the analysis of continuity of care, the principles outlined within primary and community health service delivery are applicable across the broader health system. General Medical Practice in the community, as well as Outpatient and Emergency Departments, share an interest in defining who came, what they came for, the type of service provided, did it work and how much did it cost. Previous work undertaken has, however, not tended to consider the information requirements of the non-government services of the primary and community health sector.

Another significant contribution of the CHIM to ambulatory classifications is its focus on social medicine. While primary and community health services cannot be divorced from biomedicine and its classifications schemes, these schemes apply to only a portion of the reasons for which health services are delivered. If the health system is to move beyond political rhetoric regarding wellness models for service delivery our contemporary management tools need to reflect the cultural climate in which they are developed.

The CHID Project is already liaising with projects for future Patient Administration Systems, Community Home Nursing information requirements, as well as projects developing ambulatory casemix classification, both Nationally and within NSW Health. In addition, the CHIM assists in identifying common data and functionality to inform an integration strategy, for the proposed information system, to all existing health information systems across the State.

Most importantly the CHIM provides a tool for the information system 'user' community to communicate their information management requirements to the systems developer. The generic data structure and provisional Application Architecture provides a common language from which to negotiate the system specification. This facilitated communication is expected to reduce the time spent in system specification.
4. CONCLUSION

In conclusion, it is acknowledged that validity and reliability of Issue and Activity Type contained in the CHIM will only occur once these entities are applied within the primary and community health information system. Analysis of this data, however, is expected to provide information on continuity of care within the NSW Health system; extend ambulatory casemix classifications and apply them to both government and non-government services; assist the development of ambulatory classifications which focus on the social health arena and capture the diversity within 'wellness' service provision; and, inform, review and validate existing ambulatory casemix classifications as well as significantly inform those works in progress.

In terms of an information system the key benefits of the CHIM are the identification of the interface with existing information systems, a reduction in specification time due to this common language, and development of an initial application architecture and a common language for the health system which should facilitate discourse with the information system developer.

It is anticipated that CHID as a work-in-progress will be beneficial to the development of best practice in systems development in Australia. This project warrants continued liaison with health personnel and systems designers regarding development of the CHIM into a client focused information system.

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From Regional Planning to Information Systems Design (The Lupus HealthNet Experience)

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Introduction

This paper describes the experience of the University of Calgary, the Alberta Research Council (ARC), and the Calgary Regional Health Authority (CRHA), in collaboratively developing a prototype of a computerized patient record (CPR) to deal with the chronic illness of Systemic Lupus Erythematosus (SLE). Through the creation of the SLE prototype we intend to show the potential of developing larger clinical information systems having the ability to efficiently monitor patient outcomes and effectively increase their quality of care.

The Lupus HealthNet (LHN) is a five-year project aimed at networking together the health care professionals and services that participate in the care of lupus patients in Alberta. The goal of the project is to demonstrate that users can provide and receive excellent health care with the assistance of innovative communication technology. The Lupus HealthNet will develop and coordinate education programs, clinical programs, laboratory and diagnostic services, research and referral programs and information systems related to lupus patient care. By harnessing expertise, experience, networks and technology, we hope to be able to manage the broad spectrum of lupus conditions.

Origins of Regionalization in Alberta

In 1990 a commission was asked to conduct an inquiry on the future health requirements for Albertans with respect to population trends, advances in active treatment and preventative health measures, health training and technology, consumer needs, and organizational funding structures. The result was “The Rainbow Report: Our Vision for Health”. Among its recommendation was a proposal for regionalizing Alberta’s health care system; a process which began in Alberta in 1994. In re-defining health services to meet the realities of provincial re-structuring, it has become necessary to re-examine health care delivery practices. Regionalization required changes but it has facilitated a new approach to well-being of the population which looks at the concept of a continuum of care for the patient across the various sectors of the Regional Health Authority: acute care, continuing care, public health, and private ambulatory care centers.

Despite major efforts there remain deficiencies in the ability to provide seamless delivery of comprehensive care to a regional population base. We have not had the ability to effectively plan for patient’s care and analyze the resultant outcomes. Historically this has been due partly to segregated administrative bodies, lack of cohesive strategic planning initiatives, and decreasing provincial health budgets requiring the re-allocation of funds to an already overburdened system. However new initiatives within the CRHA have attempted to address these issues by instigating strategic programmatic planning.

Regional Programs

A regional program is a network of services coordinated across a continuum of care through policy, planning, and assessment of a population’s needs. The services include organizations, individuals, operating units, and other delivery structures both inside and outside the CRHA system. The continuum of care encompasses health promotion, injury prevention, active treatment, supportive and restorative care, palliation, and teaching and research. There is
limited experience to guide the development of regional programs, thus, the CRHA is pioneering the development through an empirical approach. The relationship between the CRHA, the ARC and the University of Calgary was set up to leverage the strengths of each institution in order to develop the conceptual framework of an information strategy for the regional program structure. Primarily this will be achieved by the addition of Computerized Patient Records (CPR) bridging the gap between distributed sites and the providers that must occupy them.

**Challenges**

The challenges faced by the CRHA are significant. They must simultaneously improve health status, improve the quality of health services, decrease costs, and increase our focus on the needs and priorities of consumers. To be successful, the CRHA must consider options which will fundamentally change how health services are planned, organized and delivered. The key step in the process is the evaluation of the programs and services to access if priority health goals are being met and if expenditures are cost beneficial. The availability of comprehensive client information is critical throughout this process to support the provision of services and for the evaluation of their effectiveness. This is a cyclical process which must be repeated on a regular basis to ensure the efficacy of health care programs and services.

**Regional Needs Assessment**

In early 1996 the CRHA conducted a regional needs assessment aimed to substantiate the strategic program plan. The needs assessment process assesses the health status of the community and the community’s perception of needs. The needs assessment information is used to set broad health goals and to develop the strategies required to deal with the priority needs. Both providers and consumers belonging to the CRHA were adamant that the CRHA reform the existing plans by which they were conducting care in their ambulatory and acute care environments. One of the most plausible ways to facilitate these goals was the creation of a strategic vision that would see the grouping of all like disease sets together under a regional program. This program would be responsible for developing policies for care for each of the unique patient population bases. As a result, the assessment now acts as a baseline for planning of programs and services and can assist in identifying areas of the most cost effective health care expenditures. The LHN was already perceived as a model which was consistent with the findings of the needs assessment.

**Access to Information**

A key component in the conceptual framework of a CPR is access to relevant information about a patient or the community as a whole. The health care record’s primary function is to support the care of the individual. Fundamentally, it is based on the patient and is a coexistent list of observations about the individual’s physical, psychological, and social well being. It is made by a selection of clinicians and should contain their thought processes and their personal care plans to assist with their delivery of care. This enables providers to establish management plans, and provide patients the means to gain accessibility to information services so to enhance their role as partner in their own self-management.

Care givers and support staff must be able to access information about all services provided to assist in making decisions about the care of the patient. This is especially relevant when considering seamless delivery of care between the various aspects of care within the CRHA. If we are to provide efficient care from “cradle to grave” we need to have the ability to track the outcomes and clinical states of a patient at any given point of time.

Furthermore, planners and management must be able to use the information to analyze the effectiveness of individual programs. Efficacy of individual interventions can be measured against the desired outcomes to ensure that optimal resource allocation is maintained. This ability to provide cost benefit analysis assists managers in strategic planning to ensure that limited health care resources are being expended in the most effective ways. In other words, individual patient care and outcomes must be aggregated to provide optimal use of the information at a strategic level of program delivery.
Patient Focused Information Systems

A region wide implementation of an comprehensive information system for all programs would be too costly for existing budget allotments. In order to prove the concept of a patient focused information system and to gain support from academia, government, and private industry, the concept of the program was scaled down to create a "virtual health clinic" addressing specific health care problems. The prototype of the virtual health clinic, the Lupus HealthNet, is a community service designed to empower the patient in their role as a self manager. It is built on the existing regional communication infrastructure, and leverages equipment and knowledge from several industry sponsors. The conditions associated with Lupus and other chronic illnesses consume a majority of the current health resource and it is in these areas that the need is greatest for a coordinated management plan. This need is growing steadily as our population advances in age and these afflictions become more common.

Lupus HealthNet

The Lupus HealthNet will foster the collaboration of health care professionals over the network to solve patient issues, no matter where the patient or professional is located. It will allow care providers to operate from various facilities as well as allow patients to communicate with caregivers from their own environments. A patient will no longer be forced to come to central facility for care. The HealthNet's foundation of technology, will enable more efficient and effective information networking among health care professionals, increasing the speed at which medical situations are analyzed and diagnosed. For the patient this will mean more involvement in their care and an opportunity to become more knowledgeable resulting in increased self-management. This innovative model of health care delivery will aim to meet patients needs in terms of affordability, accessibility, integration and comprehensive service. Ultimately it will be a system that significantly lowers facility costs and staff and patient effort and time.

Conclusion

One of the principal philosophies of regional programs is to involve patients, their families, and their health care professionals in their care. We believe that the Lupus HealthNet self-management and support programs, in addition to outreach education will benefit patients and their families making them better managers of their overall care. These programs will teach them how to cope with the lifestyle changes and the day-to-day frustrations that accompany living with a chronic disease. The education of health care professionals will focus on learning about patient management plans, the latest research findings, and incorporating current clinical practice guidelines. The information system developed to support the Lupus HealthNet is driven by these objectives. By tapping into this evidence-based data systems and networking together, health care providers will be equipped to participate as part of a comprehensive, coordinated management team for the patient. Regional plans will be supported by this information system in the future.
Physician Resource Systems
Application of Clinical Workstations: Functionality and Usability

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Keywords: clinical workstation, evaluation, hospital information system

Abstract

Clinical workstations are software systems that support physicians and nurses in all their specific activities concerned with the medical care of in-patients. In the university hospital of Saarland we are testing several commercial systems whether they can give such a comprehensive support. For their evaluation we developed a list of criteria grouped in functions to support the physicians, functions to support the nurses, and general functions, together with a grading schema.

Beside scope and quality of functions the acceptance of clinical workstations strongly depends on organizational environment and human factors. To evaluate these conditions we interviewed all people concerned with the system using a checklist.

We detected the following problems (examples):

- "Facts" (new design of workflow (e.g. for examination or nursing procedures); some tasks have to be performed twice; reaction to emergencies; frequent changes of staff)

- Technical deficiencies (response times too long; due to width of display and lack of data consistency mobile data collection was insufficient (e.g. during the doctor's visit))

- Psychological factors (fear of using computers; statements like "Medical work may not be planned" or "Too few benefits by the system"; in view of increasing "transparency" no use of electronic scheduling; no sufficient understanding of workflow of automated tasks).

The consequences of this study are: introducing clinical workstations in a hospital needs, as well as a re-engineering of the business processes of the ward, a careful and intensive training of staff.

In our contribution we will present and discuss methods and results of this evaluation study.

1.0 Introduction

The development of comfortable user interfaces has led to more and more computers being used for clinical purposes in hospitals, but different names (e.g. "patient care information system" [1], "clinical workstation" [2] or "medical workplace system" [3]) express different opinions about the necessary functions and the intended purpose of computers in the clinical field (wards, ambulatory centers). In their conception and their range of functions these systems often cover some isolated aspects only (e.g. access to computer-based medical records [4]).

We define clinical workstations (CWs) as integrated software systems supporting physicians and nurses in all their specific activities concerned with the medical care of in-patients [5]. This necessarily includes access to a computerized medical records system, if such a system is available in the hospital, for input, storage, display, retrieval, and printing of information contained in a patient's medical record. The functions needed - especially for
the wards as the most important units in the medical care of in-patients - may be provided not only by stand-alone solutions but also by several servers which are integrated in a distributed hospital information system (HIS).

2.0 Methods

2.1 Criteria and Scores

Both the development and the selection of software demand as detailed a description as possible of the required functionality of CWs. For comparison and evaluation of systems we developed a list of requirements and evaluation criteria for four groups. The first group includes the functions to support the physicians, the second the functions to support the nurses, the third general functions, and the fourth the system environment.

Table 1 shows examples of the main criteria. In practical use some criteria are considered in much more detail (e.g. the item "nursing care plan"). Examples of items of the system environment are internal and external communication, configuration (customization), user interface (masks, navigation, user levels), data protection, response times, help-functions, and after-sales support.

Table 1: Examples of functions of CWs

<table>
<thead>
<tr>
<th>Functions to support physicians</th>
<th>Functions to support nurses</th>
<th>General functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documentation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anamnesis</td>
<td>Nursing care plan</td>
<td>Registration of services</td>
</tr>
<tr>
<td>Precautions</td>
<td>including Anamnesis</td>
<td>Administration of master files</td>
</tr>
<tr>
<td>Findings</td>
<td>Problems and resources</td>
<td>Archiving</td>
</tr>
<tr>
<td>Diagnoses</td>
<td>Objectives</td>
<td></td>
</tr>
<tr>
<td>Treatments</td>
<td>Interventions</td>
<td></td>
</tr>
<tr>
<td>Coding helps</td>
<td>Controlling</td>
<td></td>
</tr>
<tr>
<td>Medical reports</td>
<td>Evaluation</td>
<td></td>
</tr>
<tr>
<td>Decision support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescriptions</td>
<td>Scheduling</td>
<td>ADT-Functions</td>
</tr>
<tr>
<td>Orders for services</td>
<td>Bed management</td>
<td>Rota planning</td>
</tr>
<tr>
<td>Therapy plan</td>
<td>Distribution of drugs</td>
<td>Integration of other programs</td>
</tr>
<tr>
<td>Information services</td>
<td>Orders to pharmacy</td>
<td></td>
</tr>
</tbody>
</table>

We evaluate the scope and the quality of each function assisted by a weighting system. The weight corresponds to the significance of a function in daily work. The score range is 0 to 3 (Table 2). To grade the quality of a function it must at least exist. Some functions offered by the CWs can not be assessed in our environment. In such a case the quality is considered not to exist. Afterwards we multiply each score by its appropriate weight to get the final score for one function. Group scores are built by adding up the function scores. We end up with eight individual scores describing the offered scope and quality of each system (see Table 3).

Table 2: Grading criteria

<table>
<thead>
<tr>
<th>Weight (Value)</th>
<th>Scope (Score)</th>
<th>Quality (Score)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td>Needless (0)</td>
<td>Not sufficient (0)</td>
</tr>
<tr>
<td>Level 2</td>
<td>Useful (1)</td>
<td>Sufficient (1)</td>
</tr>
<tr>
<td>Level 3</td>
<td>Important (2)</td>
<td>Good (2)</td>
</tr>
<tr>
<td>Level 4</td>
<td>Very important (3)</td>
<td>Very good (3)</td>
</tr>
</tbody>
</table>
2.2 Questionnaire and interviews

There are some features such as personal experience with computers, attitudes towards computerized facilities, necessary reorganization of workflow, etc., which do not fit into the grading schema described above. Therefore we developed a questionnaire with about 20 items and tested it on (nearly) all users. The answers have to be considered in a final decision in a more general way because of the difficulty of using scores to evaluate them.

Along with the questionnaire we interviewed physicians and nurses. They were asked to assess the preparatory measures for the system, the user training, the configuration for the special needs of the ward, and the system support, using a grading schema with four scores varying from deficient to good. We asked them for their expectations about the system and whether they were fulfilled using predefined items (e.g. decay of workload, faster availability of information, better coordination between the ward and external service providers, help with administrative tasks). The input of free text was also allowed. The next group of questions concerned the benefits and disadvantages using the CW. We ended with questions about the philosophy of CWs and their usefulness in the clinical environment.

3.0 Application

The University Hospital of Saarland plans to equip all wards with CWs. Therefore we started tests with different commercial systems to evaluate their advantages and disadvantages in our environment. Up to now two systems have been tested: the product MediCare by MICOM and the product SC-MED by SOFTCON. Neither product covers all mentioned functions but both are suitable for use as CWs. They have a wide range of functions and can be customized.

The product MediCare runs on personal computers with NOVELL NetWare and MICROSOFT Windows. As a special feature notepads for mobile data collection can be used. The underlying database is MICROSOFT Access. The test is being carried out on a ward covering internal medicine (gastroenterology and endocrinology).

The product SC-MED runs on a UNIX server (HP-UX, System V) using the window system OSF/Motif. The data is stored in a relational database (here: ORACLE). The server is integrated in a LAN. Personal computers with X-emulation are used as workstations. Mobile data collection is not planned at present. SC-MED is being tested on a ward covering internal medicine (pneumology).

4.0 Results

Table 3 shows a summary of results (for more details see [6]) which we received by comparison of the two systems.

<table>
<thead>
<tr>
<th>Functions to support physicians</th>
<th>MediCare Scope</th>
<th>MediCare Quality</th>
<th>SC-MED Scope</th>
<th>SC-MED Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functions to support nurses</td>
<td>106</td>
<td>58</td>
<td>188</td>
<td>122</td>
</tr>
<tr>
<td>General Functions</td>
<td>122</td>
<td>93</td>
<td>142</td>
<td>106</td>
</tr>
<tr>
<td>System environment</td>
<td>24</td>
<td>19</td>
<td>56</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>162</td>
<td>82</td>
<td>193</td>
<td>165</td>
</tr>
</tbody>
</table>

Twenty-five people answered the questionnaire (7 physicians, 18 nurses). 45% had experience with computers, the others did not. Twenty-four per cent of respondents declined the introduction of a CW, 54% were open-minded, and 22% were in favor.
Almost 40% did not notice any benefits from the use of a computerized CW. The following advantages have been cited: documents (e.g. reports of findings) are easier to read (54%), greater availability of information (31%), less paperwork (23%), and the completeness of the medical record (16%).

The following disadvantages have been cited most: doubling of workload (92%), insufficient communication with subsystems (e.g. laboratory) (77%), inadequate presentation of information (screen and printer formats) (62%), response times too long (54%), organizational changes become necessary (51%), and ill-suited menus and masks (46%).

62% of respondents agree with the statement "The workflow of a ward is not plannable and therefore the use of a CW is not possible". 93% believe that basic improvements to hard- and software and better communication with other systems of the HIS are essential before CWs can be accepted.

5.0 Discussion

5.1 Methods

Some authors describe the scope of functions of CWs depending on their specific view (e.g. [7]). But these descriptions are not suitable for software evaluation. Therefore we tried to compile a comprehensive and sufficiently detailed list of functions which covers all needs of a ward together with a grading schema.

Results of interviews about their use and experience with computerized systems in clinical environments have been reported often (e.g. [8, 9]). Our technique is very similar to [9]. Due to the small sample size we used descriptive statistical analysis only.

5.2 Results

The final result (table 3) shows that SC-MED comes off better than MediCare in all groups. Scope and quality of functions as well as system administration and reliability of SC-MED were better. The potential benefit of MediCare being available for notepads for the bedside documentation could not be proved.

Although this result seems to be clear, we decided to install neither SC-MED nor MediCare. The reasons were experiences during the projects and the analysis of the interviews. Particularly the interviews revealed several problems which influenced the final assessment of CWs. In the following we discuss the most important problems.

5.2.1 Technical problems

A very important feature for CWs is the ease of customizing. It is a prerequisite to use commercially available software in distinct clinical environments. Since different specialties have different requirements the systems must offer customization of the documents, forms, lists, and outputs. This can be derived partially from the analysis of various document types (findings, reports of examination, ...). Since nearly 60% of respondents said that the customization was inadequate, this feature has to be proved rigorously.
Because in our hospital neither the central laboratory nor the central kitchen are equipped with computer systems allowing data transfer between CWs and themselves, we could not test the communication with them. However, we have connected one external function unit to each system, for MediCare the function unit endoscopy, for SC-MED the unit assessing pulmonary functions. Special interfaces were developed to transfer the administrative patient data from the patient management system to CW using a dedicated communication server [10]. Nevertheless 77% of respondents noted that the communication with subsystems was insufficient. This is understandable, since the laboratory results were not available on-line. Several authors report that the access to laboratory results is the most used [2] and the most useful [9] function of a CW.

The most important function of a CW is to display patient information [11]. However, in the present study 62% of respondents said that the presentation of patient data was not satisfactory. It was too difficult to get an overview of the course of a patient's illness or the prescribed procedures. We think that in designing the screens the potential users were inadequately consulted.

The response times of the system have been assessed as too long (54%). Therefore a quick and value-added access to information [1] was not guaranteed. The use of a more powerful hard- and software may improve this problem.

Mobile data collection with notepads (MediCare), for instance during the doctor's visit, has proved a failure because the display was too small to be practical and the processor used was too slow. 68% of staff agree that mobile data collection and presentation, using suitable equipment, would make daily clinical work a lot easier. This agrees with experiences of other authors [12].

5.2.2 Organizational problems

The introduction of CWs causes changes in the workflow. The sequence of tasks and some responsibilities may have to be changed. 51% of respondents felt this a disadvantage. Furthermore 39% reported that the systems provided too few automatisms ("defaults") for daily repeated tasks. This indicates a poor analysis of the business processes of a ward.

Most staff (61%) prefer to write information on paper instead of entering the data in the CW. For prescription writing or test ordering, it is hard to beat the speed of pen and paper [11]. New techniques of data input (e.g. voice recognition) should be tested.

During the projects all patient data had to be dealt with twice: in the CW and in the conventional medical record. Only temporarily we could help with additional personnel. Therefore 92% of respondents called this doubling of work the main disadvantage. This burden is acceptable if the benefits outweigh. But the rates of advantages cited (31% greater availability of information, 23% less paperwork) are not convincing. This points to errors in the project management.

The quality of the training courses was assessed overall as satisfactory or good (83%). However the scheduling of courses has to ensure that all staff are trained and no gap between the training and the application phase occurs. It is difficult to achieve this goal especially for physicians due to their frequent changes in a university hospital.

Another organizational problem was the introduction of a new nursing model just before our test started. The theoretical basics of the nursing process (using 12 groups of "activities of daily life") had been conveyed in a course of training. Standards for the nursing process were developed by a workgroup. It was necessary to separate the problems caused by the introduction of the new nursing model from the problems caused by the CW use.
5.2.3 Psychological factors

When CWs were introduced 55% of the ward staff had to work with computers for the first time. They were insecure because of a great fear of making mistakes and of their ignorance about the possible reactions of the program. Reluctance to use computers is still widespread. It may be overcome by careful training and provision of evidence that the use of computers yields some benefits.

The attitude towards CWs depends on the knowledge and experience about the use of computers. Since about 30% said that the preparatory measures were deficient, we assume that we should focus project management on the provision of information about possibilities and purposes of CWs and making their use as stress free as possible.

Cooperating with the physicians we found that some of them (45%) declined CWs generally, while others (38%) would use the software, if it would yield concrete improvements for the patient care. Safran reported the same experience and discussed reasons [11]. Physicians requirements differ from those of nurses, e.g. reminders, clinical guidelines, or access to scientific literature are important. Such features must be provided.

The programs tested offer appointments facilities for the external function units. The use of the electronic appointments book looks easy and comfortable. The ward staff can look in it and see busy and free dates. Although the change from the conventional kind of scheduling by phone calls and appointments book to an electronic appointments book is regarded with skepticism by both ward staff and function unit staff: if they have a very tight schedule because of emergency patients or unexpected out-patients the involved wards must be informed that the appointment must be changed. In practice an adequate response is often impossible. This problem seems to be organizational. But behind this arguments the fear of to much transparency is the true reason.

6.0 Conclusions

The summary of our investigations is: not only scope and quality of functions offered are crucial for the successful introduction of CWs, but also the requirement for ward reorganization and the consideration of "human factors". In the light of this we have decided not to use such a comprehensive CW, because the number of functions and the necessary changes make the project management too difficult, but we will try to establish a simpler solution for the wards, i.e. to begin with a basic set of functions and to add the remaining functions step by step on demand.

The first steps will be access to the patient management system for ADT-functions and - together with a computer system for the central laboratory - the possibility to order tests and to view results. Our experiences with these projects will be surely helpful to achieve this goal.

References


The Office of the Future Project: The Integration of New Technology into Office Practice: Academic Detailing through the Super Highway

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Keywords: Computer-based drug utilization, office practice, electronic academic detailer

Abstract

Effective management of drug therapy in the elderly is a challenge for primary care physicians. There are 20,400 drugs approved for marketing in Canada. Most elderly patients will fill 33 prescriptions per year, and take 5 different medications. To be a 'safe prescriber' in the 1990's, physicians need to be aware of the 33,000 documented drug interactions, 6,500 drug-disease and 3,500 drug-allergy contraindications. Inappropriate prescribing is a problem in the elderly. 12% to 46% of seniors receive at least one inappropriate prescription, and 25% of drug-related hospital admissions are due to prescribing errors. Half of all physicians will write at least one inappropriate prescription for an elderly patient each year, and one-quarter of inappropriate prescriptions will be created by the presence of multiple prescribing physicians. Academic detailing is the most effective approach to improve physician prescribing. However, it is an expensive intervention that must be limited to a small number of drugs and conditions, and it must be continued to retain its effectiveness. Furthermore it fails to address the problems created by multiple prescribers. In this project, we developed a prototype of the future office practice. Physicians are equipped with PCs and 'expert prescribing system software'. This 'electronic academic detailer' reviews all current medications for a patient, identifies therapeutic duplications, generates alerts for 50 prescribing problems that have been identified as clinically relevant by a Canadian expert panel, suggests suitable alternatives, and reviews all new prescriptions for potential problems. Information on all prescriptions received by the physicians' elderly patients is downloaded weekly from the provincial prescription claims database so that the primary physician is able to coordinate and manage all drug prescribed to their patients by all physicians. The effectiveness of this intervention is being evaluated in a randomized controlled trial of 110 physicians and about 20,000 elderly patients in Montreal. We will test whether the intervention reduces the rate of inappropriate prescribing and the rate of drug-related injuries and hospitalizations among patients treated by physicians in the experimental group.

1. Introduction

Effective management of drug therapy is a challenge for primary care physicians. There are 24,400 drugs approved for marketing in Canada. To be a 'safe prescriber' in the 1990's, physicians need to be aware of [1,2; reference therein]:

- 33,000 documented drug interactions;
- 6,500 drug-disease contraindications;
- 3,500 drug-allergy contraindications.

The quantity of information a physician has to process in order to make the best prescribing decision may become a real problem when treating elderly patients [1,2]:

- elderly fill on average 33 prescriptions a year for 5 different medications;
- 78% of them have at least one chronic disease, and 30% have 3 or more;
- 71% receive prescriptions from more than one physician during the year;
- 37% visit more than one pharmacy to fill their prescriptions.
Given this situation, it is not surprising that drug-related illness (DRI) in seniors has become a significant public health problem in Canada [1,2]:

- 12% to 46% of seniors receive at least one inappropriate prescription during the year;
- between 3% and 15% of all hospital admissions in the elderly are related to DRI;
- DRI accounts for one in a thousand deaths of people over 65 years of age;
- 50% of physicians write at least one inappropriate prescription a year;
- a quarter of inappropriate prescriptions are created by the presence of more than one prescribing physician.

Over the past decade, considerable attention has been devoted to the development of intervention programs to improve physician prescribing. Six main types of interventions have been used to modify physician practice: education, practice aids, standards and feedback, one to one consultation, and administrative policies [3]. Although the impact of these interventions on patient outcome has never been evaluated, the characteristics of interventions that are effective in changing physician prescribing have been identified. The most effective interventions are those which provide expert advice to physicians in their practice environment, typically through one to one contact between an expert with the physician (academic detailing) [4,5]. Despite evidence of efficacy, adoption of one-to-one interventions into regular quality control and intervention programs is not in evidence. Several limitations can be identified [2]. First, one-to-one interventions are costly to introduce and all interventions require on-going maintenance for continued effectiveness. Second, the feasibility of one-to-one interventions rests on the assumption that the majority of inappropriate prescriptions are attributable to a small number of physicians and only one or two target drugs are a problem. Third, all existing physician-based prescribing interventions make the assumption that the patient has only one prescribing physician, or alternately each attending physician is fully aware of all medications received by a patient. The existing evidence suggests that such assumptions are not valid [2]. General practitioners, to whom these interventions would be applied, constitute the largest sector of medical manpower in Canada; 49% of the 15,236 physicians licensed in Quebec in 1993. The cost of instituting and maintaining one to one interventions such as academic detailing at a provincial level would be considerable.

In sum, different approaches are needed to optimize prescribing in the elderly. Ideally, a method is needed to accurately track and record drugs currently dispensed, to document current medication in the patient's chart, to review problems with existing and new prescriptions during the office visit, and to provide the physician with an up to date expert resource that could be used to select a drug treatment. One solution that has proven to be highly successful in enhancing adherence to practice guidelines is office-based computer-assisted expert support systems for patient management [6,7]. Although, a number of computer-based drug utilization review systems and drug information networks have been installed [8], the effectiveness of these interventions has not been evaluated. In fact, none of these systems have been implemented as support systems for the prescribing physician [5]. Rather, pharmacists and government review groups have been placed in the unenviable position of having to review the appropriateness of a physician's prescribing habits without knowledge of the clinical indications or context within which the drug was prescribed. Furthermore, because no clinical information is available, review at this level must be limited to potential drug interactions and excess drug doses. Thus pharmacy and government based drug utilization programs cannot screen for potential drug-disease or drug-allergy contraindications and these types of prescribing problems constitute a substantial proportion of potentially preventable drug-related problems [9].

2. MOXXI: a new intervention

MOXXI (the Medical Office of the XXIst Century, also known as ROPNAPA) is a new intervention program to optimize physician prescribing. MOXXI is expected to reduce the occurrence and cost of potentially inappropriate prescribing and drug-related morbidity in the elderly. This Quebec initiative takes advantage of the new available technology to provide primary care physicians with 1) a mechanism for tracking patient medication, 2) surveillance and feedback on inappropriate medication, and 3) expert assistance with prescribing decisions in their practice setting.
MOXXI is comprised of two components:

Component #1. Comprehensive information on prescribed medication.

The provincial prescription claims data is used to provide physicians with a dynamically updated list of all medications dispensed to each of their elderly patients including those prescribed by other physicians. The prescription claims database is generated from data collected by the Regie de l’assurance-maladie du Quebec (RAMQ), the health agency which administers the provincial drug insurance program (which covers prescription drug costs for all persons 65 years of age or older). Each time a pharmacist dispenses a drug to an elderly person in Quebec, he/she invoices the RAMQ for the reimbursement of the drug cost and dispensing fee. To be reimbursed, the pharmacist must record the patient’s Medicare number, the date of dispensing, as well as the drug, dose, duration and prescribing physician. The RAMQ verifies the validity of the submitted data, reimburses the pharmacy, and retains the electronic record of invoice information in the prescription claims database. In our own independent validation study of this database, we found that drug and patient information was highly accurate (approximately 93% of all prescriptions) [10], certainly much more accurate than that obtained by record review [11] or patient self-report [12]. Thus, the provincial prescription claims database contains one of the most comprehensive and accurate sources of information on drugs dispensed to elderly Quebecois, and prescription drugs constitute approximately 95% to 97% of all drugs used by the elderly [13]. A detailed plan for conducting this component of the intervention has been developed in collaboration with the RAMQ.

Component #2. Prospective drug utilization review and expert prescribing assistance.

A software system has been developed by Clinidata and the Quebec Research Group on Medication Use in the Elderly to provide: a) prospective automated surveillance of each patient’s current drug regimen for potential problems in the drug, dose, or combination of medications prescribed in relationship to documented health problems, b) surveillance for potential problems in new drugs prescribed, c) expert opinion on problems in a patient’s medication regimen and advice on alternate appropriate drugs and doses, and d) expert prescribing assistance and information on drugs approved for marketing in Canada (indications, dosing, side-effects, contraindications and recommended follow-up). CMS (Clinical Management System) is a multi-faceted prescribing, patient documentation, and information support software. There are several distinctive features of this system that make it a unique prod
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MOXXI is a prototype of the future office practice. In this intervention, primary care physicians are equipped with a PC and CMS. The patient's clinical data are entered into the software's patient profile system so that drugs that are contraindicated by existing disease can be identified. This also serves as a patient record-keeping system for the primary physician. CMS downloads automatically patients' drug information via datapac from the RAMQ database server in Quebec city and conducts an automated drug utilization review on each patient's drug regimen. The database server contains information on all prescriptions dispensed to the physician's elderly patients. This information is abstracted from data recorded in the claims received by the RAMQ from all pharmacies in Quebec who dispensed drugs to Medicare registrants in the provincial drug insurance program. When the patient arrives in the office, the physician is provided with a printed list of the patient's current drugs. Potential problem prescriptions are signaled, the consequences of the problem are identified, and alternate therapy is suggested. The physician uses CMS to add, modify, reorder or delete drugs from the current list. The system immediately alerts the physician to any problems, but allows an override to proceed with the intended prescription. A printed prescription is generated, signed by the physician, and brought by the patient to the pharmacist to be filled in the usual way. Pharmacies who dispense prescriptions to elderly patients file claims with the RAMQ, and this data is downloaded to the database server in Quebec City, thus providing a dynamic update of medications prescribed and dispensed by physicians and pharmacists in Quebec. Therefore, the primary care physician is able to co-ordinate and manage all drugs prescribed to his patients.

3. The MOXXI project: evaluation of the new intervention's effectiveness

The primary purpose of the MOXXI project is to determine whether interventions using computer technology to provide primary physicians with expert advice and feedback in their practice setting are efficient to reduce the occurrence and cost of potentially inappropriate prescribing and morbidity in the elderly.

The effectiveness of this intervention will be evaluated in a randomized controlled trial of 110 physicians in the Montreal area and about 20,000 of their elderly patients. During the experiment, the 55 physicians who are randomized to the experimental group will use the MOXXI system when caring for their elderly patients. Information on diseases and allergies of these patients will have been retrieved from their medical chart and used to create an electronic chart on the physician's computer. Physicians randomized to the control group will also receive a computer and patient management software but they will not receive the
prescribing software before the end of the experiment nor will they have access to the provincial prescription claims database. The study will start November 1st, 1996 and will last for 12 months. The effectiveness of the MOXXI system will be judged by comparing the rate of inappropriate prescribing and adverse patient outcomes (hospitalization rate, rate of fracture and injuries, mortality) in the experimental and control groups.

4. Preliminary results: Differences between participating and non-participating physicians

To be eligible for inclusion in the study, a physician has to be registered with the College des medecins du Quebec as a general practitioner, have a private practice located in one of the three selected health care regions of the Montreal area (Island of Montreal, Monteregie, Laval), see elderly patients in their practice, be in active practice at least 3 days per week, and be 30 years of age or older (the highest risk group for inappropriate prescribing [17,18]). Furthermore, to avoid problems of independence violations in the analysis, only one physician in a group practice was included. Of the 2730 licensed general practitioners in the three regions selected, 681 (24.9%) were found to be eligible to participate in the study. 110 of these were recruited in the MOXXI project.

Participating physicians of the Island of Montreal were on average 47.4 ± 6.4 years old and had graduated in 1973 (± 6.2 yr.), with most participating physicians having graduated from Universities of Montreal or McGill (63.1%) or foreign medical schools (25.0%). The majority of participants were male (83.7%) and French speaking (68.5%). Participants' practice profile was largely office based, with a mean of 78.7 ± 22.7 % of their practice time spent in a private office setting. The only significant difference between the characteristics of participating (n=92) and non-participating physicians (n=375) was their age. Participating physicians were slightly younger than non-participants (mean age: 47.4 Vs 49.9, respectively p<0.005).

All patients in each physician's practice who are 66 years of age or older at the beginning of the intervention, and who have visited the physician at least twice in the 12 previous months, are eligible for inclusion in the study. Participating physicians have a combined eligible population of 25,768 patients.

5. The future of the intervention in Quebec

A provincial advisory committee, composed of key players in the Quebec health care system, has been set up to study the feasibility of applying the MOXXI system province-wide, and to help identify and define important parameters that will guide policy makers in this endeavor. This committee includes representatives from the Quebec Senior Citizens Federation, Quebec College of Physicians, Quebec Federation of General Practitioners, Quebec Pharmacist Order, Association of Quebec Pharmacist Owners, RAMQ, Quebec Advisory Panel of Pharmacology, Montreal Regional Health Board and the Quebec Ministry of Health.

An expert committee is also attached to the project to study the ethical and legal issues related to the transmission of confidential provincial information to primary care physicians and the need of new guidelines and legislation in this area.

6. Conclusion

MOXXI may be the answer to health professionals', government's and public's expectations. In nowadays context of cuts in health care budgets, this project proposes a solution to improve medical services provided to the population while reducing costs of delivery. Besides the expert prescribing software, other options will be added to the tools available to physicians. In the near future, physicians will have computer access to courses of continuing medical education, will be able to consult specialists, obtain education material for their patients, bill the health care agency directly, or obtain results from laboratory tests. Depending on the success of MOXXI, the probability is high for participating physicians to become the first physicians to integrate computers in the everyday practice of their profession.

7. Acknowledgments

We would like to thank all people that made the MOXXI project possible. In particular, people at the Regie de l'assurance Maladie du Quebec (G. Soucy, D. Carmicheal, J. Barry, J.F. Germain, and many others) for whom we have the greatest respect for their considerable expertise, Catherine Marquis (project coordinator) and her army of dedicated workers without whom MOXXI would be impossible, Tracey Reid and Jimmy Fragos for data analyses and computer maintenance. The MOXXI project is supported by the Quebec Electronic Highway Fund, the Fonds de la recherche en santé du Québec, the Medical Research Council of Canada, Clinidata, the Seniors Independence Research Program (Health Canada) and the Quebec College of Physicians.
8. References


Physician Resource Data Bases: An Essential Tool for Planning

Lynda Buske and Sheri Newton

Abstract

Physician resource planning activities have increased dramatically in Canada since the release of the Barer-Stoddart report, "Toward Integrated Medical Resource Policies for Canada" in 1991.

One of the key concepts of the Barer-Stoddart report is the "medical career lifecycle", beginning with entry to medical school and ending with exit from practice. In order to apply this concept in a planning context it is essential to have a current information base that will contain data on numbers of physicians, where they are, what they do and how active they are. In addition, a longitudinal capability is important for understanding issues such as retention and attrition.

The objective of this paper is to review and assess recent initiatives in the establishment of physician resource data bases in Canada by medical associations, governments, licensing bodies, certifying colleges and other groups with respect to comprehensiveness and comparability of key data elements, their ability to address key policy questions in physician resource planning and to identify opportunities for collaboration and linkages.

1.0 Background

Physician resource planning activities are occurring in every Canadian province to ensure that an appropriate number and mix of active physicians are accessible by the public. The profile of active Canadian physicians at any given point is difficult to accurately assess. It is necessary to know not only who and where Canadian physicians are, but also what they are doing.

Planning tools that are used to examine physician resource issues should be placed in the context of the "medical career lifecycle". This lifecycle, described in a 1991 report by Barer and Stoddart entitled "Toward Integrated Medical Resource Policies for Canada", can be generally categorized as pre-medical undergraduate studies, medical school training, residency training, active practice and retirement. Access to timely and accurate information along the lifecycle is needed to understand issues such as retention and attrition. Such information allows policy analysts to make more effective decisions regarding which modifications to the system should occur so that the future needs of Canadians, with respect to physician services, can be met.

2.0 Who and Where They Are

Numerous organizations in Canada maintain physician resource databases that apply to the lifecycle stages. Data are first collected during the training phases of the lifecycle at the undergraduate level by the Association of Canadian Medical Colleges (ACMC) and at the post-graduate level by the Canadian Post-MD Education Registry (CAPER). AMC collects basic demographic data such as date of birth, name, and gender, along with a great deal of academic qualification data. CAPER collects the demographic data and focuses on type, level, dates, and location of medical specialty training.
Once in practice, a physician's profile is developed by many organizations. Physicians must register with the appropriate provincial/territorial licensing body. Licensing bodies have demographic data and also type of license information. For payment purposes, physicians register with the medical care plan in each province or territory. The Canadian Institute for Health Information houses the National Physician Data Base (NPDB) which is based on provincial/territorial administrative billing data from fee-for-service physicians. Initiatives are underway to complement this dataset with profiles of physicians who are paid on a salaried, sessional or capitated basis.

In most cases, physicians will be members of the provincial/territorial medical association which represents them in negotiating agreements with the government. Through this membership a physician can also become a member of the Canadian Medical Association (CMA) which is the voice of Canadian physicians at the federal level. The CMA supplements information received from individual physicians with the information obtained from the licensing bodies and provincial/territorial medical associations to maintain a file containing all physicians (both members and non-members) who are or have been licensed to practice in Canada. This file is updated on a daily basis to ensure accuracy.

Depending on his or her qualifications, a physician may be a member of the College of Family Practitioners of Canada, the College des Medecins du Quebec, or a fellow of the Royal College of Physicians and Surgeons of Canada, or belong to any number of specialty societies and groups. These organizations usually collect at least basic demographic and mailing information.

Southam Business Lists maintains a mailing list of physicians that it markets to pharmaceutical companies, marketing firms, and organizations conducting research (e.g., universities). One of their clients of longest standing has been Health Canada which has maintained a historical database of physician supply for the better part of the last three decades. Recently this database became the responsibility of the Canadian Institute for Health Information (CIHI) which has undertaken the redevelopment of the information system to increase its capacity to perform quick queries and its flexibility in analyzing supply, mix and distribution trends.

With so many provinces embracing the decentralization of their health care systems through the establishment of regional and district health authorities, there is a growing requirement for physician planning at the community level. The ability to compare physician counts (and full-time equivalents) across the country for communities of a particular size is a relatively new requirement. The physician databases at the CMA and CIHI contain at least one postal code attributable to individual physicians that can be grouped into identifiable communities such as individual census metropolitan areas or communities of a set population size (e.g., 50,000 - 100,000). Census population data can be applied to the physician counts to calculate the physician to population ratios in each setting.

3.0 What They Do

A variety of methods are used to determine physician activity levels during the 'active practice' phase of the lifecycle. At the national level, since 1982, the CMA has conducted a periodic physician survey, called the Physician Resource Questionnaire, to collect information on the number of hours physicians spend on particular types of activities each week (e.g., direct patient care, administration, research, teaching, continuing education, etc.), and the number of weeks worked per year.

The Physician Resource Questionnaire also collects statistics on the number of hours that physicians who practice general/family medicine spend on activities that may, in some communities, be performed only by specialists, (e.g., surgery, anaesthesia, emergency medicine). These physicians are asked how many obstetrical deliveries they perform in a year. These data show interesting trends such as the steady decline in the percentage of primary care physicians performing deliveries in both rural and urban settings.

In 1995, the Royal College of Physicians and Surgeons of Canada started to collect data on hours worked through a survey of all certified specialists. The purpose of this survey was to update the 1988 National Specialty Physician Review report, which counted and grouped specialists based not only on their certified specialty, but on their functional specialty as well through a peer review process. The 1988 report attempted to identify shortfalls based on physician to population ratios for individual specialty groups. As an alternative to peer review, in the 1995 study, the physicians were asked to report any other areas or disciplines in which they practice and to indicate the
percentage of clinical time spent in each. Reported disciplines (that are not recognized specialties) have been distilled into approximately 60 areas of practice that the RCPSC felt were worthy of separate analysis (e.g., AIDS/HIV, transplantation, pain management). Results of the 1995 study will be available in fall 1996.

Despite the admirable response rate of the RCPSC study (over 80%), there are still a significant number of non-respondents that will require the expenditure of additional resources to collect information through other means. In contrast, the provincial/territorial licensing bodies are in an ideal position to collect very accurate and up-to-date information through the process of annual license renewal. A few such organizations, such as the College of Physicians and Surgeons of Alberta and the Collège des médecins du Québec collect profiles on physician activity as a condition for license renewal.

Statistics Canada collects data on physicians on a sample basis, through its Census, by asking for occupation on the long form which is administered to one in five households. However, the data cannot be analyzed by specialty of physician or type of professional activity and therefore is limited in its applicability to workforce planning.

The provincial/territorial medical care plans possess extensive administrative data bases that allow them to process fee-for-service physician claims, to see what physicians are doing as a whole and to monitor the billing practices of individual physicians relative to others in their peer group.

Through the NPDB, CIHI can measure physician activity in several ways. Because the information in the NPDB is based on fee-for-service billing data, utilization measures such as the number of services per physician and payments per physician are possible. In addition to the head counts of all physicians who submit at least one fee-for-service claim to medicare in the year, the NPDB assigns a full-time equivalent status to every physician based on specialty specific annual billings to the medical care plans. The National Grouping Categories within the NPDB, collapse the thousands of provincial and territorial fee service codes into relatively standardized categories of services. It is possible to compare services or payments per physician at a specialty-specific level.

Despite efforts to standardize procedural codes for double counting and irregular unit measures, services remain difficult to compare across jurisdictions and across specialties. In their development of a full-time equivalent measure, CIHI decided that services were inadequate in terms of reflecting intensity or value of a service. Expenditures, on the other hand, tended to be a measure of services weighted by fee values. Therefore, the NPDB has concentrated its efforts on measuring full-time equivalent physicians based on payments made to individual physicians during a fiscal year. Each physician is assigned an FTE count based on his earnings relative to specialty specific benchmarks.

4.0 Who Wants to Know

The CMA handles approximately 800 ad hoc requests each year for physician resource information from many sources including provincial/territorial medical associations, private companies, universities, individual physicians, and the media. The number of requests to this one organization demonstrates the need for an accurate picture of where physicians are and what types and level of professional activities they are engaged in.

In their 1991 report on physician resources, Barer and Stoddart, recommended improving the creation and provision of information relating to physician resources in Canada.[1] Without such information, policy analysts cannot make effective decisions about such issues as number of medical school and residency places, number of graduates of foreign medical schools to allow into Canada to practice medicine, or whether to set up retirement policies. Such information is especially useful in determining which population areas are underserviced due to a lack of physicians.

254
5.0 Challenges in Measuring Supply

Although it would seem a straightforward exercise to keep track of approximately 55,000 active physicians, it is compounded by many factors. One of the most difficult elements of physician supply is the measurement of physician attrition out of the active pool.

It is recognized that there are time lags in any database between the occurrence of an event and when it gets registered within the system. However, this is compounded if there is little incentive for the physician and no strong mandate for a particular organization to collect the necessary data. For instance, there is some incentive for a physician leaving the country to notify his or her medical associations as they may qualify for a prorated reimbursement of their annual membership fees. A physician, however, may not necessarily notify all the organizations that maintain data on them, especially if they do not intend to return to Canada.

A similar situation arises when a physician retires. As a profession, physicians do not have a clearly defined age of retirement. As well, they have the option to gradually reduce their activity levels over a number of years. This means that they may well keep up a license to practice medicine (and therefore be counted as active) while perhaps treating only a handful of patients each year.

Other problems can occur in trying to count active physicians who are providing patient care. These include: 1) physicians who are concurrently licensed and registered with medical care plans of more than one province/territory; 2) physicians who maintain their license but are providing no patient care (e.g., full time administrators); and 3) physicians who move abroad directly upon graduation from post-MD training.

One of the most common methods of representing the supply of physicians relative to population needs is through the use of physician to population ratios. These ratios act as a very broad indicator of whether or not the number of physicians is increasing or decreasing relative to the patient population. Criticisms of this type of measure include: 1) lack of adjustment for differing population needs (e.g., age/sex); 2) services may be obtained outside population area; 3) critical mass issues are not addressed, (i.e., a minimum number of physicians may be required in an area to provide adequate professional support); and 4) the variation in service provision levels of individual physicians is not taken into account.

6.0 Data Linkages

The variety of physician databases has led to an inevitable duplication of information. There have been very few attempts to create formal linkages among data collecting organizations due mainly to concerns over ownership and confidentiality. As well, in the past, it was very difficult, for technical reasons, to merge data from very different hardware and software environments. However, with many technological problems being quickly overcome, there may be more opportunities for linkages.

Confidentiality of individual physician records is naturally a concern given the personal or sensitive nature of the information collected by some organizations. This could be examination results, individual earnings, practice profiles in terms of the types of services provided, hours worked each week, etc. However, technology has enhanced our ability to ensure confidentiality when linking information systems.

However, some core information required for physician resource planning does not require the use of the more confidential types of information. At the most basic level, there is a need to accurately count active physicians and to know what community they are serving. The information required for this is not of a particularly sensitive nature. It is essential to know the physician's specialty (at a minimum, certification-based), an up-to-date address, and if they are still in active practice.

As there is no satisfactory method yet to link the various databases, record matching, when approved, is done by name, date of birth, and other demographic variables, and often requires considerable manual intervention to address problems like mismatched records (e.g., physicians who have changed their name). A commonly proposed solution to eliminate these problems is the development of a unique physician identifier that would remain the same through
undergraduate and postgraduate training, active practice, and into retirement. Ideally the number would not be reused when a physician leaves the system to allow for re-entry (e.g., returning to active practice from abroad).

There have been some successful informal linkages between datasets at the national level. An example is the recent tracking of physicians from the completion of postgraduate studies into practice. With the help of CMA data, CAPER has begun locating where physicians are practicing a few years after graduation. If the physician cannot be found in the CMA database, CAPER can consult a database purchased from the American Medical Association that includes all physicians practicing in the United States who received their MD graduation in Canada.

Other opportunities may present themselves via use of the Internet to make portions of the databases available to physician resource planners. Search engines could facilitate the compilation of physician resource data from a variety of sources.

7.0 Key Policy Questions

Beyond being able to accurately report the current situation with respect to the physician workforce, it is also essential to be able to test how certain policy initiatives will affect physician supply and productivity in the future.

To do this, researchers have developed projection models of varying degrees of complexity to estimate both the physician and patient population of the future based on current available databases. A recent attempt in this area has been the Physician Resources Evaluation Template developed by the CMA as an Excel application. It allows the user to vary the magnitude of entry and exit variables by year to estimate physician supply by age, broad specialty and gender to the year 2011. Entry variables include cohorts such as postgraduate exits, physicians recruited from abroad, and physicians returning to Canada while exits incorporate physician attrition through retirement, death, migration, etc. Inputs to the system are adjusted over time for changes in gender, age, and GP/specialist distribution. Work is underway to expand the template for estimating supply at the provincial level.

8.0 Summary

In summary, it would appear that despite their shortcomings, there are some very comprehensive physician databases being maintained in Canada by many organizations. Linkage possibilities are endless and should be championed by multistakeholder groups within well-established confidentiality parameters. This efficient use of resources can assist policy planners in making effective decisions that allow the needs of Canadians with respect to physician services to be met appropriately.

9.0 References


National and Provincial Strategies

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Keywords: Health Information Management, process, health systems, health reform

Abstract:

In November 1991, the Report of the Royal Commission on Health Care and Costs, Closer to Home, was released. The report articulates that although the health system in BC is one of the best in the world, there is room for improvement. Effective use of information should assist in improving and restructuring the operation and management of the health system.

British Columbia has been in a state of Health Reform since 1993. Effective information management is a critical component of this strategy. On November 1, 1994, the Ministry of Health formed the Health Information Management Project (HIMP). The project was formed to initiate a process of changing the way information is managed in the health system.

This paper will outline the process undertaken by the Ministry of Health through the Health Information Management Project to initiate change in the way information is managed and how it hopes to maintain the momentum gained in the project to integrate good information management practices into all aspects of the health system.

I.0 INTRODUCTION

1.1 Purpose:

The purpose of this paper is to outline the process undertaken by the Ministry of Health through the Health Information Management Project to initiate the way information is managed and how it hopes to maintain the momentum gained in the project through its achievements.

1.2 Background

In November 1991, the Report of the Royal Commission on Health Care and Costs, Closer to Home, was released. The Report articulates that although the health system in British Columbia is one of the best in world, "...there is room for improvement, and improvement will mean resetting priorities, reallocating funds and removing the fortress walls." The Commission stated that the system needs to be better managed and funds need to be better allocated. Effective use of information should assist in improving and restructuring the operation and management of the health system.

In 1993, the Ministry of Health responded to the Royal Commission Report with its health reform strategy. Effective information management is a critical component of this strategy. Information management (IM) is not the actual data or computers used in the health system but rather the dynamic, ongoing process of managing information as a valuable resource. Long term strategies adopted for health information management in the province will have a direct bearing on the success of health reform as these strategies impact the ability to:

- decentralize and manage the health system;
- integrate resource allocation, management and service delivery at the community, regional, and provincial level;
- evaluate the effects of changes in the health system on the health of the population; and
- manage the overall costs of developing and operating information systems.


**2.0 HEALTH INFORMATION MANAGEMENT PROJECT**

On November 1, 1994, the Ministry of Health announced the formation of the Health Information Management Project (HIMP). The project was formed to initiate a process of changing the way information is managed in the health system. The Ministry assumed the responsibility of leading the process and working with the health system to ensure that there is a common vision and strategy to best manage information in the health system.

**2.1 The Process**

The following section outlines the process that the Ministry of Health undertook to reform its information management.

**2.1.1 Team Approach**

The first step in the process was to create a team responsible for the success of the project. The HIMP project team consisted of senior management. Executive directors from each of the major organizational units of the Ministry of Health (Corporate Programs, Strategic Programs, Regional Programs and the Medical Services Commission) participated in the process. The project team reported to a steering committee comprised of the Associate Deputy Minister for Regional Programs, Assistant Deputy Minister for Corporate Programs and the Project Director. Senior level commitment and support was essential.

**2.1.2 Vision, Goals and Strategies**

The Health Information Management Project began the planning process by developing a vision. The vision for Health Information Management in B.C. is effectively and efficiently managed information that enables informed decision making to achieve the results desired in our health system.

The vision was translated into specific goals that represented what was to be achieved over time. As part of the planning process, HIMP developed a set of strategies which reflected the team's assessment of the best approaches to move towards the vision. A complete description of the vision, goals, principles, and strategies is available from the Ministry of Health in a document entitled Vision for Health Information Management in British Columbia.

**2.1.3 Stakeholder Buy-In**

Draft versions of the vision, goals, and strategies were developed by the project team. These were then presented to various stakeholder groups for feedback. Comments were incorporated and the results were presented to an Advisory Task Force on information management. The Advisory Task Force was made up of health system representatives from around the province representing varying disciplines. In addition, the project team involved various areas of the Ministry of Health. Communication was essential to success.

**2.1.4. An Action Plan**

Using the strategies as guidelines, action plans with specific targets and time frames were developed to move towards the vision. More specifically, several information management projects to operationalize the strategies were initiated. The following framework was used to address different areas of information management.
A. Process. The projects under this category initiated processes or mechanisms to enable the management of information among multiple parties in a diverse environment. They did not actually attempt to identify the information, or how the transfer/sharing of information would take place. Rather, these projects set up the structure so that issues could be addressed. The projects under the process category included:
- Coordinating Council
- HIMP Tactical Plan
- Standards Council
- Regional Systems Coordinators

B. Training, Education, Support and Awareness. The projects under this category educated and trained health information users in the access and use of data as well as in the concepts of information management. Projects under this category included:
- Internal and external training
- Education and awareness

C. Information Needs and Access Requirements. The initiatives in this area addressed the identification of data that met the business needs. In particular, the data to meet priority areas for the Ministry of Health such as financial management and reporting, utilization management, strategic planning, as well as funding formulae were the focus. In addition, there was an initiative to examine access requirements with respect to the public, regions, and the Ministry as well as the data that is required for decision support systems. The projects fell into the following areas:
- Information needs
- Financial management
- Public, regional and ministry information access
- Decision support requirements
D. Corporate Data Administration. Projects in the Corporate Data Administration area ensured that requirements identified through group C projects were consistently defined and could be shared. Projects in this category were in the areas of:

- Data definitions
- Data administration dictionary - tools and process
- Data administration organization
- Health industry data administration support

E. Applications. Group E projects were the development of applications based upon the requirements identified by Groups C and D. Applications are the vehicles by which data is collected, accessed, and or processed. The specific projects in this category were:

- Public access technology
- Consolidate data warehouses and decision support systems
- Reporting technology
- Implement new data collection
- Client Registry
- Ministry of Health systems strategy

F. Infrastructure. The infrastructure category included those initiatives that would create the basis for specific information systems to be built at a later date. Regardless of minor changes in direction these projects will form the building blocks and set the foundation for effective information management. Projects in this category included:

- HealthNet/BC
- Personal Health Number
- Privacy/Security

2.1.5 The Coordination

One of the keys to the success of the project was the people. Not only was it necessary to have a senior level champion, but also to have a team that worked closely together. Each category, A-F had a project manager, and in particular project managers for groups C-E worked very closely together as these initiatives were tightly linked and interdependent. In addition, each project had an executive sponsor.

HIMP meetings were held weekly for the first six months of the project and later they were held biweekly.

3.0 The Achievements

In the eighteen month duration of the Health Information Management Project, it successfully initiated a number of processes to change the way information is managed in the health system. In particular, the following achievements are noteworthy:

3.1 A Shared Vision

The initial work for HIMP focused on developing a vision for health information management in B.C. The vision was developed through a consultative approach, and was recently modified by the BC Health Information Management Coordinating Council. The vision document is based upon several components, namely a vision statement, values, guiding principles, and desired outcomes.
3.2 Coordination

The HIMP project established a number of structures to provide a coordinated approach to information management and to exchange information on initiatives in the Ministry and in the regions. These are:

- The BC Health Information Management Coordinating Council

- The Health Information Management Coordinating Council is a body formed last year to coordinate information management activities for the BC Health System and to ensure alignment of regional and Ministry plans with the overall health system information management plan. In addition, the Coordinating Council works with the Standards Council to give a regional perspective regarding priorities. Members act as key contacts for their regions for the dual purpose of providing a communication link and for resolving issues.

- The BC Health Information Standards Council. The Standards Council is made up of regional and health sector representatives with a mandate to focus on the identification of standards and guidelines to promote effective and efficient sharing of health information. These standards and guidelines are expected to focus on data, applications, and technology. The Standards Council recommends standards to the Ministry of Health but the Ministry is responsible for setting these standards.

- Regional Informatics Coordinators. Regional Informatics Coordinators (RICs) have been designated for different geographic areas of the province and play a key role as liaison between the Ministry and regions. These coordinators assist Regional Health Boards, Transition Teams and the BC Health Information Management Council by:
  * supporting the identification of regional information needs and strategies; and
  * providing advice and guidance on information and systems initiatives.

3.3 Accessible, comparative information

The HIMP Project worked on a number of initiatives to support access to consistent, comparative information needed to manage the business functions of the health system. Specifically, considerable effort has been directed to developing a minimum shared data set, developing a prototype of a health data warehouse, and in compiling an inventory of the key indicators to meet information needs of the Ministry of Health in support of such priority areas as financial management and reporting, utilization management, strategic planning, and funding allocation methodologies.

Minimum Shared Data Set

The HIMP Project worked closely with stakeholders to define a basic set of data (the Minimum Shared Data Set) that is the key to managing business functions in the health system. The data set represents the information which would be shared with regions and communities and among different divisions of the Ministry. Elements of this minimum data set must be consistently defined to enable any meaningful sharing.

A Health Data Warehouse.

A Data Warehouse provides secure access to information across disparate data bases running on different machines which are currently using different operating systems and different technologies. Access to relevant, timely, and consistent information is a key requirement of health system governors, managers and service providers. A Health Data Warehouse prototype was developed under the sponsorship of the HIMP Project, to demonstrate the feasibility of improving the collection and sharing of data throughout the health system.
Key Indicators to Support the Role of the Ministry of Health

The HIMP Project compiled a listing of key indicators for the Ministry to monitor regional performance and to ensure programs’ outputs are at an acceptable level. The key indicator project built upon the principle that key indicators require a context if they are to have meaning and act as signposts that trigger further action. Several methods for developing a context for data include making comparisons across jurisdictions, making comparisons over time, and setting benchmarks for expected performance, based on historical performance or targets.

3.4 An Infrastructure

Several projects have either been initiated or supported by the HIMP Project. These initiatives serve as the building blocks for information systems to be developed at a later date. Specifically, the HealthNet/BC and Client Registry/Personal Health Number (PHN) Projects serve as a foundation that will remain regardless of minor changes in direction.

HealthNet/BC

The HIMP Project initiated HealthNet/BC, a data communications network which will link all health system participants. It can speed communication among health care providers, and lead to higher quality care. This information “highway” will allow for quick, secure and cost-effective exchange of data and information between any connected sites.

About 260 hospitals and Ministry field offices are connected to HealthNet/BC. Regional planners can decide how to expand on this foundation, with Regional Informatics Coordinators available to provide advice and guidance.

Implementation of HealthNet/BC will continue to be coordinated by Ministry staff using the services of the public and private sectors. This approach will provide significant savings on the network costs that are, or will be, incurred by individual organizations entering into separate contracts with network suppliers.

The Client Registry/Personal Health Number (PHN)

The HIMP Project also supported the Client Registry which is a central repository for detailed demographic information. It includes an individual’s name, address(es), date of birth, gender, and phone number, all indexed by the Personal Health Number (PHN). Implementation of the PHN has provided the vehicle to promote sharing of client information across diverse information systems, given FOIPP considerations.

The Registry’s goal is to become the most accurate and accessible source of demographic information for all health system clients. The Registry will help to reduce the duplication of resources required to maintain demographic data in several information systems. It will also improve care providers’ ability to track patients/clients through the health system. Several projects are currently planned to connect hospitals and care providers to the database.

3.5 Cost-effective management of information

The HIMP Project worked towards providing the regions and the Ministry with the training, education and support required to locate, acquire and use health information for critical developmental and operational activities. A specific working group (Training, Education, Support, and Awareness otherwise known as TESA) was formed with the objective of supporting the Ministry and the regions in the acquisition and management of information.

TESA also served as a communications link between regions with regard to ongoing information management initiatives and other HIMP projects.
TESA has implemented several projects:

- A referral service, the Statistics Referral Line, has been set up for directing health system stakeholders to the statistics and information they need. This initiative fulfills a growing need for a "central clearinghouse" for regional information requests.

- The Health Information Management Bulletin, distributed regularly to approximately 1800 health system stakeholders has established a forum for regional information sharing. The Bulletin provides updates on current informatics initiatives throughout the Province, as well as listing contacts and resources to assist TESA clients to better meet their information needs.

- An inventory has been prepared of health information management training, education, and support resources currently in place in the Ministry that are available to requesting organizations.

3.6 Security and confidentiality of information

The HIMP Project focused some attention on the issues of security and confidentiality. One of the key principles articulated in the vision document is that information will be secure and confidential. More specifically, the principle states that only information that is required will be collected and it will be available only to those who need to know it and are authorized to have it. In addition, the vision document specifies that privacy legislation is one of the key building blocks critical to achieving the goals set for health information management.

The HIMP Project has embraced the concepts articulated in the Freedom of Information and Protection of Privacy legislation and has gone one step further by focusing one of its projects on articulating when personal information in health situations can be disclosed, as per section 33 of the FOIPP Act.

Two of the coordinating structures that were initiated under the leadership of HIMP, the Standards Council and the Coordinating Council, have both identified security and confidentiality of information as a priority issue. The Standards Council has recommended that the Canadian Organization for the Advancement of Computers in Health (COACH’s) "Security and Privacy Guidelines for Health Information Systems" be adopted as an interim guideline.

Lastly, the Ministry of Health requires that a privacy impact statement be prepared for all new information systems which store or manage personal information.

4.0 CONCLUSION

The HIMP Project has initiated a journey which will continue for several years to come. As indicated in the quote by Sir Winston Churchill, "this is not the end ... but it is, perhaps, the end of the beginning".

It is hoped that the information management strategies developed by the HIMP Project will strengthen the ability of the regionalized health system and other health stakeholders to more effectively plan for, manage and deliver health services. During the short time HIMP was underway, it successfully started a number of processes to improve the way information is managed. Some of these initiatives are localized within the Ministry of Health but may serve as examples or tools upon which the regions may build. Other initiatives are province-wide in scope and will support the entire health system.

As information management requires a corporate perspective, the Ministry of Health will continue to provide leadership in this area, working in close partnership with the BC Health Information Management Coordinating Council and BC Health Information Standards Council. The experience of the HIMP Project reinforces that successful management of information in the health system will depend on the continued cooperation and commitment of all stakeholders.
Mental Health Applications

Chair: Derek Walker
Strategies to Meet the Health Information Needs of People with Intellectual Disabilities

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Keywords: Health Information, intellectually challenged, multimedia

Abstract

The purpose of this paper is to discuss strategies used by the Health Information Resource Centre (HIRC) in Prince Edward Island (PEI) to meet the health information needs of people with intellectual disabilities. HIRC is a provincial health promotion initiative designed to improve access to information to all residents of PEI, and thereby providing them with the opportunity to increase control over, and improve their health.

Findings of a 1995 needs assessment conducted in PEI by HIRC indicate that individuals with intellectual disabilities have difficulty accessing health information because they have not been told how or where to obtain it, they have problems understanding the information, or it is in an inappropriate format. Research supported by Choice and Opportunity (a Federal/Provincial initiative aimed at developing a new way of supporting the participation of persons with intellectual disabilities) provides evidence that individuals with mental handicaps and their families have difficulty accessing the information they need to be full participating members of their communities.

Using funding provided by Choice and Opportunity, HIRC is designing programs to meet the health information needs of individuals with intellectual disabilities by eliminating barriers to accessibility. Strategies employed include: providing health information in plain language; using adaptive technology; developing a portable Health Information Kit; and providing up-dated information about specialized and generic services, general community programming, providers and locations that are available to them.

Outcomes of the strategies and suggestions for improving access to health information for this population will also be offered.

1.0 Introduction

1.1 Health Reform in Prince Edward Island

Throughout the 1990's, Prince Edward Island has been developing a comprehensive reform of the health care services provided by the Province. Reform has resulted primarily from the need to adopt a broader understanding of health, to shift the focus from an illness model to a wellness model and to control escalating spending. The mission of the Health System is to "support community's efforts to promote, protect, and enhance the physical, social, emotional, intellectual and spiritual well-being of our population, within the resources available to the community" [1]. The goal of health reform is to promote self-reliance and a better quality of life for Islanders. Underlying principles such as self-care, mutual aid and the creation of healthy productive environments enable individuals and communities to improve health.

In the spring of 1993, the Province of Prince Edward Island adopted the report of the Transition Team on Health Reform entitled "Partnerships for Better Health" [1]. This plan led to the creation of the Health and Community Services Agency and five regional boards were created with the responsibility for the planning and delivery of health and social services across Prince Edward Island. This model is viewed as being unique, and reflects a holistic approach to health and social services. Although the approach is viewed as being unique, PEI faces the same problem all provinces, indeed many countries around the world, face. We all must develop strategies to deal with the
issues of reduced funding and increased dependency on our health care systems. For example, in 1987 the per capita cost for health services in PEI was $1,500. In 1995 the expenditure was about $2,000 for every person in the province. As in most parts of Canada, efforts to reduce expenditures is occurring, e.g., shifting care from institutions to the community in such areas as mental health and addiction services. To effectively move programs into the community, services must be made available to support these programs. As well, consumers of costly health care services need to be equipped with the tools to enable them to become more self-reliant, and therefore, more healthy and less dependent on the Health System.

1.2 Background on the Health Information Resource Centre

One goal of health promotion is "self-reliance" within the community: to develop programs that increase the availability of health information and thus the potential for self reliance and informed choice in lifestyle issues, self care and treatment. In a Community Needs Assessment conducted in 1995 [2], Islanders told the PEI Health System, "Yes, we want to take more control over our health, but if we don't know about services or where to go for information - how can we become healthier?" Consumers, community organizations, and health service providers were asking for more information about health. In other surveys conducted across the province, Islanders said that appropriate information can help them to improve health, prevent illness, reduce dependency on the health system, and live happy healthier lives [2,3,4,5,6,7]. As public access to information was limited and fragmented, an accessible provincial health information resource centre was developed. The Centre was developed by the Health and Community Services System in partnership with the Island Community. The Centre is serving as a focal point in the development and implementation of a multi-faceted, widely accessible health information network.

The Health Information Resource Centre (HIRC) is a provincial health promotion initiative designed to improve access to information to all residents of PEI, and thereby providing them with the opportunity to increase control over, and improve their health. Services provided by the Health Information Resource Centre include: free access to information on a wide range of health topics and specific diseases; information on health system and community resources; community outreach programs; and researching and meeting the health information needs of special populations such as children, seniors, persons with disabilities, and low income single moms.

1.3 People with Intellectual Challenges

People who are intellectually challenged enjoy the same rights and benefits as do other Canadians and they have the same degree of control as other Canadians over decisions which affect them and influence their lives. As with the general population, people with mental handicaps are not getting the information they need to make decisions about their health. People with intellectual disabilities have difficulty accessing health information because they have not been told how or where to obtain it, they have problems understanding the information, or it is in an inappropriate format [8,9].

Choice and Opportunity is a joint project of the Governments of Canada and Prince Edward Island and the Prince Edward Island and the Canadian Association for Community Living aimed at developing a new way of supporting the participation of persons with an intellectual disability. Using funding provided by Choice and Opportunity, HIRC has designed programs to meet the health information needs of individuals with intellectual disabilities by eliminating barriers to accessibility.

2.0 Where we are in the Project?

Choice and Opportunity is attempting to redesign existing programs and delivery mechanisms while at the same time providing more opportunity for individuals who have a mental handicap to make decisions about how they want to receive support and services, and assisting generic agencies and community organizations to be inclusive of persons with a disability [10].

There is evidence that individuals with mental handicaps have difficulty accessing the information they need to be full participating members of their communities. In PEI, people with mental handicaps and their families are experiencing a great deal of frustration and anxiety over the lack of support systems in place for them [8,9]. The Health Information Resource Centre is a new resource in the province, which with appropriate equipment and
resources will provide the opportunity for individuals with mental disabilities to access information, probably for the first time in their lives.

By facilitating access and providing information to people with mental handicaps, the information needs of other specific populations (e.g., people with learning disabilities) and the general public will be met. However, if special measures are not taken to ensure that appropriate equipment and information sources are in the Centre and other areas of the province, the needs of individuals with mental disabilities will be met only in a very limited way.

The Health Information Resource Centre is helping to move the Choice and Opportunity project forward by providing a new support resource to individuals with mental handicaps and their families. Through the reallocation of resources the Centre will allow for easy access to health information. Information written in plain language and available in an accessible format will be provided, and where it does not exist, developed.

The latter could be achieved by ensuring that the information provided is at a suitable reading level and that the appropriate technology (computers/software) is available to facilitate access to the information.

2.2 Demonstration of the Model

The model being developed will ensure that individuals with intellectual disabilities have access to planning support that is separate from service delivery in order to plan and manage their resources. The Centre will play a key referral role for the target population, i.e., to facilitate access to support in the area of health. As well, through the Health Information Resource Centre’s partnership with the Provincial Island Helpline, the Centre can assist in meeting the support needs of individuals and support networks. The Island Helpline is a free, 24 hour, confidential, bilingual telephone service that provides information, support, and help in a crisis to all Islanders of all ages.

The demonstration project will produce a method that will allow intellectually challenged people to easily access information available in the Health Information Resource Centre. The project will use a multimedia computer system and develop applications we have dubbed the "Smart Access System" (SAM). SAM will path a user to one of two series of applications. The first will be for the intellectually challenged. It will allow for easy access to health information both written and spoken in plain language. The second series of applications will be designed for the easy maintenance and update of the system. This will include a easy sound capture, editing and positioning, and pamphlet scanning feature designed for a health service provider or educator to interact with and update the program.

SAM will appear on a large touch screen computer monitor located on a desk in the Health Information Resource Centre located in Charlottetown. The user will only see the screen and the speakers mounted on the sides. When the user approaches the system, SAM will invite the user to touch a moving object on the screen and speak back to the user welcoming them. Once the user is introduced to SAM, they will be led to the video/audio clips, written text or the graphic needed to explain the health issue the user wants to know more about. The user can access information on the following seven broad topics:

1. What does my body need to be healthy?
2. Where do I fit in?
3. What can I do?
4. How to stay safe?
5. What can I learn?
6. How can I enjoy life and do my best?
7. The super directory of resource personnel for the specific topic.

The user will only receive information at a basic level. They will also be given the local name and phone number of a resource person responsible for providing in depth information on the specific health issue they are researching. For example, someone who is interested in finding out more about healthy eating will get basic information on Canada’s Food Guide using SAM. They will also be provided with the name and number of a local community nutritionist they can call for more information. As well, they will be given the name of an educational video on healthy eating they can borrow from the local Media Centre.
SAM is built in modular fashion so that other areas of information can easily be added as required. It is also portable (CD-ROM, Windows95 based), and therefore can easily be setup at sites or events across the province. To complete the project, the program is being developed in four phases over a 33 week period.

4.0 Next Steps

An Alpha test model of SAM will be completed by late September, 1996. During the Alpha test 10 adults with intellectual disabilities will test the system. They will give feedback on the method of use and the pertinence of current information to the developers of system. The feedback will then be analyzed and necessary alteration will be made to the system.

By mid-December, SAM will be Beta tested with 25 adults who are intellectually challenged from across PEI to locate any faults in the system. Any weaknesses found during the Beta test will be corrected by December 31, 1996. After a three month trial period at the Health Information Resource Centre, SAM will be cloned and moved out to other communities on PEI for local access.

Feedback from users will be a vital component of the system. There will have to be continuous adjustments to the system as more demands are placed upon it. Programs like SAM are never static. Needs may change in terms of information required, levels of comprehension, as well as potential applications. Because the users' demands continually change, the system must be flexible, easy to change, and inexpensive to adjust.

SAM could be placed in schools, libraries, the universities' school of nursing, hospitals, clinics or other community locations, possibility even onto the Internet for truly universal access. Research and evaluation will be conducted on the impact SAM has on changing peoples health care.

5.0 Conclusion

Through SAM, the intellectually challenged individual will have increased access to health information, including information about available health services, i.e., enhanced access in terms of format, location and comprehensibility. They can use this information to make more informed choices about how they access services, manage illness, and use health as a resource for living. Enhanced decision making power around their own health will allow people with intellectual disabilities to actively participate in health care and to provide for their own well-being as do other Canadians.

In the context of present health reform in Prince Edward Island and its emphasis on enabling people (to do with, not for), increased access to information will promote increased self-reliance and a better quality of life for people with intellectual challenges in Prince Edward Island.

References


Health Status Determination

Chair: Jim Coward
Harmonisation of Regional Health Data Requirements in the South Pacific

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Keywords: public health surveillance, indicators, regional health information

ABSTRACT

The South Pacific has 22 diverse countries and territories which receive various levels of technical assistance, training, and financial support from international, regional and national agencies. To support various aspects of these activities, the agencies currently request health data from the Pacific Islands countries and territories (PICs) on systematic bases in two major fields: health programme monitoring and disease surveillance. There is currently little consultation or integration between the agencies. Communication exists mostly in terms of the exchange of various types of processed information such as reports, circulars and other publications. The Inter-agency Meeting on Health Information Requirements in the South Pacific took place in December 1995 in Noumea, New Caledonia to discuss potential for more integration and cooperation in order to ease the pressure on the data providers (the countries) and improve the relevance, quality and timeliness of regional health information in the Pacific. As part of the effort to deal with the problems of both the pressure on data providers and the low quality and availability of good health information, we have developed methodological tools for evaluating both health indicators and diseases subject to surveillance in order to ascertain those most suitable for public health surveillance.

1.0 Introduction

Public health surveillance typically differs from other sources of public health data such as epidemiological studies, health surveys or administrative records in terms of data collection method, mode, volume and frequency; reporting procedures and channels; type of data analysis and information dissemination, costs and human resources involved [1, 2]. It is "the ongoing collection, analysis and interpretation of health data, closely linked with the timely dissemination of these data both to those providing the data and to those who can apply the data to control and prevention programs" [3]. While public health surveillance is quite different from the other sources, there are crucial links between them, for example, epidemiological surveys validating surveillance data. Where these links are missing, or weak, they must be strengthened in order to enhance the decision-making process within public health. This paper, however, focuses on the area of regional public health surveillance and on the selection of a set of core indicators which could be ideally used at both regional and national levels for ongoing measurements of the health status of Pacific Islands populations, and the relevant decision making based on such information.
2.0 Background

The South Pacific has 22 diverse countries and territories, who receive various levels of technical assistance, training, and financial support from international, regional and national agencies such as the South Pacific Commission (SPC), the World Health Organization (WHO), UNICEF and the Centers for Disease Control and Prevention (CDC). The agencies regularly request health data from the Pacific Islands countries (PICs) for health programme monitoring and disease surveillance. The agencies supporting various aspects of health in the PICs are all bound to the monitoring of public health programmes in which they are involved. Three agencies have ongoing, regular, regional disease surveillance activities: SPC, WHO and CDC.

Despite the fact that these various organisations have overlapping mandates and are in search of the same goal (that is, the health of Pacific Islands populations), there is currently little consultation and integration in the planning and implementation of the regional health surveillance activities. Communication of the processed information exists in terms of (a) reports and feedback materials between the PICs and the various individual agencies; and (b) information bulletins, circulars or similar publication, mostly between agencies. Despite this limited exchange, there is nothing like a planned regional public health surveillance system network.

The lack of coordination and integration has subsequent harmful effects. Good public health practice is based on sound decisions made possible by accurate, timely and relevant information. In the Pacific concerns on the quantity and quality of regional level health data have been raised many times by agencies like UNICEF, WHO and the SPC, and by the health professionals from the Pacific Islands countries themselves.

The agencies are not able to properly monitor the development of key public health programmes at national and regional levels (for example, immunization programmes and environmental health) nor the progress towards regional public health goals (such as reduction of measles mortality, or rate of low birth weight) because regional public health surveillance was not sound enough. There is not enough data available, and what there is, is often of questionable accuracy and is not reasonably timely (to list just a few of the problems).

The frustrations of the PICs are from the opposite end: the demand for health information is too high and there is not enough that appears to be done with that information. The sentiment has been often echoed that nothing is done with the pages of data sent in regularly. The excessively high demand is partly due to duplication of the requests, and so the countries have asked the agencies to increase their level of integration and coordination of their data needs and requests.

In December, 1995, the SPC hosted the Interagency Meeting on Health Information Requirements in the South Pacific, cosponsored by UNICEF and WHO (two of the other major stakeholders). Its aims were to start the process towards decreasing the pressure on data providers by a concerted effort towards integration of regional health data requirements, and enhance decision-making by improving the relevance, quality and timeliness of the health information available in the Pacific region. It brought together representatives from several regional agencies, Pacific Islands countries and outside resource people from Hawaii, Australia and New Zealand to discuss the challenge ahead. At IAMHIR, a Pacific Public Health Surveillance Working Group (PacPHSWG) was formed to continue the work described here.

3.0 The Pacific scene of health status indicators

Before the meeting, the authors conducted a review of the available information from most of the international agencies involved in the region. We compiled a list of 178 indicators currently required from the PICs by WHO, UNICEF, UNDP, CDC and SPC, for health monitoring and evaluation, excluding (for the sake of manageability) indicators on the provision of health care, health expenditures, health policy, socioeconomic and education. Despite this broad exclusion, we do not underestimate the importance of these other areas. The distribution of these 178 indicators is listed in Table 1. The largest category is “communicable diseases”, which includes diseases surveillance (that is, numbers of cases).
### Table 1

#### Health Status Indicators in the Pacific - Subject Areas

<table>
<thead>
<tr>
<th>Subject</th>
<th>Number of different indicators</th>
<th>Requested by more than one agency</th>
<th>% of indicators in this area requested more than once</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communicable diseases</td>
<td>67</td>
<td>28</td>
<td>42%</td>
</tr>
<tr>
<td>Demography</td>
<td>19</td>
<td>10</td>
<td>53%</td>
</tr>
<tr>
<td>Maternal and Child Health</td>
<td>25</td>
<td>9</td>
<td>36%</td>
</tr>
<tr>
<td>Non-communicable diseases, injuries and violence</td>
<td>18</td>
<td>7</td>
<td>39%</td>
</tr>
<tr>
<td>Nutrition</td>
<td>18</td>
<td>5</td>
<td>28%</td>
</tr>
<tr>
<td>Health status (general)</td>
<td>14</td>
<td>3</td>
<td>21%</td>
</tr>
<tr>
<td>Environmental health and social conditions</td>
<td>17</td>
<td>3</td>
<td>18%</td>
</tr>
</tbody>
</table>

The lack of coordination between agencies is demonstrated by the overlap of some indicators. One third of the indicators were requested by more than one agency; one tenth were requested by 3 or more. The amount of overlap is the greatest in demographic indicators. Study of the pool of indicators shows that they are not each specific of a unique health event or issue. In thirteen instances, a single health problem or field of activity (for example, low birth weight or access to safe water) is measured in two or more different ways. One purpose of the multiple measurements is to provide refinement of information on a problem but in this list of indicators sometimes definitions are not only vague but as well are only slightly different and do not bring in new elements to analyze.

At this stage, the data providers' point of view deserves to be recalled. As a matter of fact, a conceptual aspect (such as definitions, terminology) may need to be considered as well, besides the quantitative approach emphasized in the introduction when stating the problem of lack of integration between requesting bodies. There is little doubt that when the differences in measurements are not expressly meant to increase the understanding of common public health problems, it can easily cause confusion at data collection levels and beyond. Apparent differences in definitions may not be recognized as different by data providers which leads to the question of which definition is actually being used.

The 178 health status indicators cover a rather wide range of data, therefore data collection will vary significantly depending on data sources, purpose and mode of collection, specificity of the information wanted, frequency and type of analysis required, expertise and resources necessary. As a result, not all data "required" are amenable to public health surveillance.

The objectives of the IAMHIR meeting were to select a core set of health indicators relevant to public health surveillance, and to move towards better coordination and integration of regional public health surveillance. In order to facilitate the evaluation of the indicators, the authors developed two methodological tools: (a) a set of criteria meant to appraise the appropriateness for a disease to be subject to surveillance; and (b) pursuing the same idea of a series of criteria, combined in order to determine whether a given indicator is relevant and useful for public health surveillance. The ultimate selection for inclusion into a regional core set and the definition of the set itself would be used primarily on the objectives of the surveillance, and on a comparative analysis of the diseases and other indicators identified.
4.0 The methodological tools

4.1 Selection of diseases for surveillance

The highest number of multiply demanded indicators is in the field of communicable diseases, and represents 42% of the total pool of indicators used at the regional level to monitor communicable diseases, conditions and syndromes. It essentially covers the incidence and mortality of 14 diseases, out of 21 monitored at the regional level. Communicable disease control and prevention, especially of Expanded Program on Immunization (EPI) target diseases, have historically been attached to public health surveillance. Even though health is not merely the absence of disease in a community, the burden of diseases, communicable or not, on the Pacific communities remains considerable, and the majority of public health programmes aim for the prevention and control of diseases. For these reasons, we decided that disease surveillance, though an important part of the core set of indicators, deserved to be treated separately.

We developed a score-based system for the selection of diseases for surveillance that aim to evaluate the relevance of a disease, condition or syndrome, against the public health surveillance objectives. This framework is designed to be used at the national level, by the countries in deciding on their disease surveillance priorities. In doing so, we drew on the experience of A.O. Carter at the Canadian Laboratory Centers for Diseases Control [4].

Our chief concern regarding the selection of any indicators is usefulness for decision making at both regional and national levels. Keeping this in mind, we developed the following public health surveillance objectives:

- to provide estimates on the magnitude of incidence and mortality of diseases, conditions or syndromes under surveillance;
- to monitor trends of the diseases, conditions or syndromes under surveillance, and detect changes indicating potential needs for appropriate action;
- to properly identify outbreaks for timely investigation and control;
- to allow for the assessment of the effect of disease control measures, providing relevant information for re-programming more appropriately focused public health interventions.

After drafting the theoretical model, we pre-tested its pertinence, feasibility and acceptability at country level, in collaboration with Dr. Michel Germain, Director of Health Services ("MÉdecin Inspecteur de la Santé de la Direction Territoriale des Affaires Sanitaires et Sociales") in New Caledonia. We used the framework to modify the list of diseases under surveillance in New Caledonia, which was scheduled for revisions. Through this process, we modified and improved the list of criteria. The sixteen criteria are listed in below:

Selection Criteria for Diseases Under Surveillance

International context
1. Surveillance interest for WHO and EPI target diseases
2. International Health Regulations

Frequency and severity
3. Incidence
4. Hospital costs
5. Mortality
6. Case-to-death ratio
7. Socio-economic impact (mainly work absenteeism and long term disability)
8. Risk perception (public, decision-makers, media, health personnel)

Communicability and potential for epidemics
9. Communicability
10. Epidemic potential
11. Vaccine preventability
Operational interest
12. Necessity for immediate action
13. Usefulness as a health indicator
14. Amenable to public health measures
15. Priority status (with decision-makers)

In the discussions at IAMHIR, the criteria were further modified and defined. To use the framework, each of these diseases is scored according to each of the criteria, and then ranked with all of the other diseases under consideration. The importance lies in the relative position rather than in the absolute score. This method for the selection of diseases for surveillance is not intended to be fully objective. However, we believe that it provides an original and reliable standardized method, with enough flexibility for being used at both regional and national levels, providing plenty of opportunity for ongoing refinement and improvement through field epidemiology studies and hands-on training.

The epidemiological transition from a prevailing pattern of communicable to non-communicable diseases, mostly in terms of mortality, has been extensively described and documented in the Pacific since the early 1980s. Despite this transition, the regional health information requirements currently favors communicable diseases heavily over non-communicable, lifestyle-related diseases. To our knowledge, with the exception of Cancer Registries, none of the existing regional disease surveillance systems include non-communicable diseases.

4.2 Selection of Health Indicators for surveillance

The authors suggested a similar framework for selection of health indicators, as for the selection of diseases under surveillance, on a points-based ranking system, bearing in mind the public health surveillance objectives, as well as other principles as acceptability and affordability. We believe a standardized criteria is essential to identify a standardized set of indicators which would ensure: (a) regional standards for public health surveillance - through reference tools and guidelines; (b) flexibility to allow different communities to decide on target-levels tailored to their specific situation and priorities; (c) public health surveillance to be planned and operated at operational level, in harmony with regional data requirements; and (d) better planning of resources for complementary health information activities that are not appropriate for public health surveillance and are more specific to the needs of a specific programme or agency (for example, programme management information systems, focused epidemiological studies, programme-specific cross sectional surveys). In developing this part of our proposed method, we referred to a CDC experience identifying a set of 18 health status indicators for public health surveillance in the United States.

5.0 Future Perspectives

5.1 Foundations of regional health information

In working towards better coordination and the establishment of a regional surveillance framework and network for the Pacific, there are a few basic principles that are imperative for success.

First of all, before becoming regional health data, any data is national health data, by definition. There is little use for the countries to spend resources collecting data that they have no use for. The only reason a country or territory would be able to sustain the necessary efforts to collect, analyze, interpret and disseminate health data is because national health professionals and decision-makers are sure of the usefulness of these data for their own purposes.

The second important point is that a regional initiative must be truly regional in its approach, and therefore as comprehensive as possible. A regional surveillance framework must be: planned in concert with all interested bodies; managed and implemented in collaboration between groups; and monitored with a common concern for an ongoing and overall improvement of regional public health surveillance.

Finally, isolated, sectoral or opportunistic activities have little chance of having a significant impact on the health of Pacific Islands populations; this is true for public health programmes and public health surveillance alike. Through the IAMHIR meeting and subsequent PacPHSWG, and by proposing methods and tools for a common approach to
public health surveillance at national and regional levels, the aim of the SPC Community Health Programme is to contribute to a concerted approach to regional surveillance. There is a need for a regional surveillance framework and it is well on its way. It is, in our view, a prerequisite to any improvement of public health surveillance in the Pacific region; within a framework, a network may flourish and activities be integrated; within a network, activities may be expanded and regional surveillance may become real. With both a framework and a network, public health surveillance in the Pacific becomes sustainable.

5.2 Actions towards regional health information

There are three crucial actions needed to bring about sustainable, useful public health surveillance in the Pacific. Momentum has been built up, and it is crucial to keep it going. As well, there are many available opportunities that are not always taken advantage of; these must be used and maximized by the stakeholders (PICs and agencies alike). Finally, the third key to success is to secure financial and institutional support.

At the IAMHIR meeting, a Pacific Public Health Surveillance Working Group (PacPHSWG) was formed to keep the momentum built in four days of discussions going. Since then, the working group has met twice to continue discussions. All of the stakeholders agree that more consultation with the Pacific Islands countries is imperative to the success of this initiative. The PacPHSWG is working towards a Pacific Public health surveillance framework. The IAMHIR participants made a commitment to endeavor to keep up the communication and collaboration started in Noumea.

To be successful, it is important to build on available opportunities. If they were based on a defined framework and more coordinated approach, public health surveillance activities may expand in PICs in a more consistent and useful manner, for the PICs and the region: for example, the experience built in surveillance in some parts of the Pacific may be usefully applied in others; findings from a field study carried out on one country could complement the information gathered in others; the skills acquired by some Pacific Islanders may be used in other countries or territories. Exchanging information and skills would create a network such as a Pacific Public Health Surveillance Network.

Telecommunication technologies have evolved rapidly during the past ten years. Some of the most modern means are readily available at low cost in the Pacific. The PEACESAT satellite communications system allows free international communications and data transfer in an area where the regular satellite telephone system is prohibitively expensive. Through PEACESAT and other available, cost effective technologies, all countries have the potential for email and electronic data exchange, as well as affordable teleconferencing. Email has already been implemented in many of the PICs; nearly all have at least one PEACESAT station where they could receive electronic data. With planning, these and other telecommunication networks in the Pacific provide an invaluable opportunity for supporting the networking of information within the Pacific Public Health Surveillance Network.

Against the background of a sound framework and regional network, with reference methods and tools available in-country and regularly improved, the development of a field epidemiology training programme could reasonably be explored in association with national and regional health training institutions (for example, Fiji School of Medicine, University of Auckland, Department of Community Medicine). The development of a Pacific Field Epidemiology Training programme would greatly contribute to make national a regional surveillance sustainable.

Although meant ultimately to generate savings by preventing certain segments of the health expenditures and improving efficiency of the health programmes, public health surveillance has a cost. This might be felt as a serious obstacle, in particular when starting up surveillance activities at country level. In the end, though, the investment in integration and coordination will lead to better, more efficient and effective use of public health surveillance resources.

The PacPHSWG may play an essential role in preparing and submitting appropriate project proposals to institutional aid donors. We believe funding proposals issued by a consortium of international agencies and Pacific Islands countries would be very strong ones, as Aid donors should be appreciative of the coordinated efforts put into the planning, implementation and evaluation of regional projects. These proposals could be seen as even stronger if they associate national, and/or regional training institutions.
The IAMHIR meeting was the first step in a long process. Exciting progress was made there, and it was the first time that such a group got together to specifically discuss regional health information in the Pacific. The challenge now is to keep the ball rolling, and to work towards a unified Pacific public health surveillance network.

6.0 References


MONI: Monitoring of Nosocomial Infections

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Keywords: monitoring, surveillance, nosocomial infections, microbiology reports, MONI.

Abstract

Recording, recognition, and prevention of nosocomial infections are the main responsibilities of a hospital infection control unit. To fulfill these tasks, this unit needs information from diverse sources (e.g. symptoms, antibiotic therapies and risk indicators from clinical records, microbiological and virological reports from the laboratory, drug costs from hospital pharmacy). MONI (MONitoring of Nosocomial Infections) is an intelligent database and monitoring system for surveillance and detection of nosocomial infections. The main features of the system are the automatic detection of and calling attention to certain critical situations, such as possible hospital-acquired infections, risk factors for the patient, diseases to be reported, etc. (monitoring). Main goals of the system are reduction of infection rate and of nosocomial deaths (improvement of quality in patient treatment), shortening the time of stay in a hospital, use of cheaper and/or less antibiotics (decreasing costs). MONI provides means to define relevant medical data (germ names, antibiotics, department names, monitoring rules, etc.) in a dictionary which can be updated interactively. The core of MONI is the monitoring module. On data acquisition, it checks if one or several monitoring rules match the entered data. Examples of situations which demand knowledge-based monitoring rules are: (1) suspicion of nosocomial infection, (2) infection at a normally sterile site, (3) a lab report indicating that a patient has been treated with an ineffective antibiotic, (4) possible choice of a less expensive antibiotic, and (5) infections of two or more patients in different wards with the same bacteria. Routine use of MONI was started in February 1996 at the Vienna General Hospital (2200 beds), the teaching hospital of the University of Vienna Medical School.

1. Introduction

Nosocomial (hospital-acquired) infections (NI) represent a significant cause of prolonged inpatient days and additional costs. Studies performed by the U.S. Centers for Disease Control and Prevention (CDC) estimate that in 1992 in the U.S. two million patients acquired NI, that 19,000 deaths were directly caused by NI and that additional 58,000 deaths could be indirectly attributed to complications caused by such infections [1, 3, 4]. In Austria, there is no comparable reporting system. Based on U.S. data and other published data, the impact of NI in Austrian hospitals was estimated to be in a range of 2.8 - 4.5 billion ATS (0.25 - 0.41 billion US$) with a death toll of 2,550 directly attributed to NI each year [13]. Recording, recognition, and prevention of NI are the main responsibilities of a hospital infection control unit. To fulfill these tasks, this unit must collect information from diverse sources, e.g. patient's symptoms and signs, microbiological and virological test results, and application of antibiotics. Because of the large amount of data, a computer system is required for the management and evaluation of this information. As has been demonstrated in the SENIC-study [11, 12], effective infection control programs rely on surveillance of NI combined with communication of surveillance results to the clinicians. Programs with this 'active surveillance' were able to reduce infection rates by up to 36%, programs without active surveillance caused an average reduction of 6% (and hospitals with no infection control program faced an increase of NI by 18%). A 6% reduction of NI rates proved to be a financial break-even point for running an infection control program.

281
MONI (MONitoring of Nosocomial Infections) is an intelligent database and monitoring system designed for surveillance and detection of NI. Data can be entered into the system manually as well as transferred automatically from external information systems. The main features of the system are the automatic detection of and calling attention to certain critical situations, such as suspicion of NI, risk factors for NI, diseases to be notified, etc. (monitoring). By use of MONI, the quality of patient care is increased by reducing infection rates, hospital stays and deaths attributable to NI. These features include clues for better adaptation of antibiotic therapies to laboratory findings, for use of the cheapest antibiotic in a given set of clinical circumstances, for avoiding unnecessary therapeutic or prophylactic schemes etc. Before the decision was taken to develop MONI, other developments in this domain were evaluated, e.g. HyBase and INKO-XPS (commercially available), WHOCARE and EPI-Info (public domain software), HELP, Salt Lake City and GERMWATCHER, Washington University, St. Louis (research systems), and various locally developed, specialized computer systems [2, 5, 6, 8, 9, 10]. They were either not suitable for the complex requirements of the Vienna General Hospital (VGH) or not transferable. MONI is being developed at the Department of Medical Computer Sciences for application at the VGH (2200 beds), the teaching hospital of the University of Vienna Medical School, which is one of the largest hospitals in Europe.

2. Design of MONI

MONI is based on a relational database. All modules of the system are placed around this database. First, there is a basic module for recording and storing of data, that allows manual data input, automatic data transfer, and archiving. The archiving part of this module helps to move data from the database to an external storage device, thus saving disk space and improving database performance. A second module provides retrospective analysis by means of configurable tables with standard items. Resulting tables can be selective for various parts (e.g. specified departments, patients, germs, etc.). In addition this module supports single database queries. The core element of MONI is the monitoring module which communicates with a layer between data input and database. On data acquisition, it checks if one or several monitoring rules match the entered data. Processing of a rule is possibly deferred depending on the complexity of the rule, and the actual and estimated workload of the system. Some rules with extensive computing time can be processed in background operation, e.g. overnight. Examples of situations which demand knowledge-based monitoring rules are: (1) suspicion of NI, (2) infection at a normally sterile site, (3) infection due to bacteria with unusual antibiotic sensitivity patterns, (4) a lab report indicating that a patient has been treated with an ineffective antibiotic, (5) possible choice of a less expensive antibiotic, (6) infection which is required to be reported to state and/or health authorities, (7) patients receiving prophylactic antibiotics longer than medically indicated, and (8) infections of two or more patients in different wards with the same bacteria [5].

Decisions for or against the assumption of a NI are made on the basis of agreed rules (CDC, NNIS) [7]. The core data elements of MONI are organized in a set of tables (dictionary for names of microbes, antibiotics, departments and wards, monitoring rules, etc.), in which hierarchies of terms can be formed. This dictionary is used by all modules of the system and can be updated and extended at any time, even during use. Thus, all definitions are standardized for all parts of the system, and there is no free text which can be spelled in different ways. This dictionary can be organized and maintained by the user in a way that it perfectly matches the local situation. Automatic data transfer from external information systems is made possible by tables that translate between different code systems and can be adjusted to local requirements. The system design allows the user to adapt the configuration of the program for use in other hospitals and institutions. Since this system is meant to administer patient data, security is an important element of its design. User identification is required every time any part of the system is used. Several user levels (data entry, physician, system management, etc.) and restriction to different data sections (e.g. specific departments) are possible.

3. Structure of the project

To facilitate realization, the complex project was split into four subsequent parts: Stage One covers the basic components of the system comprising a stand-alone system with manual input of selected microbiological patient data, basic analysis features, the dictionary for standard terms, user identification, backup and archiving functions, and prototypes of monitoring functions. Analysis is carried out with predefined standard tables which can be viewed within MONI and exported as ASCII files for subsequent examination and graphic interpretation by means of commercial analysis software (e.g. Microsoft Excel, SAS, etc.). The system has been designed for two modes of operation: (a) single personal computer and (b) multiple personal computers connected by a local area network. Stage Two's main feature is automatic data transfer from the microbiology information system into MONI, thus
reducing manual data input to a minimum. A flexible table editor facilitates analysis, and stored data are extended by additional items. Stage Two features improved data quality, extended analysis and extended monitoring functions. In stage Three, the system is enhanced in several sections (more microbiological data items, and virological and clinical data elements). For each section, automatic data transfer is established as far as possible, supported by necessary manual data input facilities. Stage Four includes extension and full integration of intelligent monitoring functions. Switching on and off, definition, changing, and deleting are possible in a user-friendly way during operation of the system.

4. Results

Stage One of MONI has been in operation since February 1996. In the preparatory phase, difficulties resulting from the large size and diversity of the VGH (about 1000 addresses of wards and other medical entities/units) and from the enormous number of possible microorganisms (at present a list of 1300 names) had to be overcome. Now the lists are established and structured in a hierarchical manner. By implementing specific features which are triggered by the contents of the database, the speed of analysis functions was noticeably increased such that even with an average personal computer (486SX25 processor) results were achieved within an acceptable period of time. Due to shortage of staff and other resources, at present surveillance is restricted to specimens with high clinical significance (especially blood cultures). Even in its abridged version, this new system allowed us to reveal the resistance distribution within Staphylococci, which are predominant in blood cultures (Table 1). An important feature of analysis in MONI is that identical microbial isolates from one patient are detected and counted only once. A stepwise analysis beginning with overall results (number and types of grown microorganisms; wards with positive blood cultures), then selecting for microbial species and wards which were frequently involved, helped us to spot a small number of 'problem areas' in our hospital. This helped to decide where to concentrate the manpower of our small infection control unit. In the case of MRSA (Methicillin resistant Staphylococcus aureus) the numbers of reported cases decreased subsequent to, and hopefully as a result of, our intervention.

<table>
<thead>
<tr>
<th>Antibiotic</th>
<th>S. aureus (19)</th>
<th>S. epiderm. (61)</th>
<th>other (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Penicillin G</td>
<td>11</td>
<td>10</td>
<td>38</td>
</tr>
<tr>
<td>Oxacillin</td>
<td>68</td>
<td>38</td>
<td>63</td>
</tr>
<tr>
<td>Gentamicin</td>
<td>68</td>
<td>40</td>
<td>88</td>
</tr>
<tr>
<td>Clindamycin</td>
<td>74</td>
<td>44</td>
<td>75</td>
</tr>
<tr>
<td>Rifampicin</td>
<td>95</td>
<td>92</td>
<td>100</td>
</tr>
<tr>
<td>Fusidic acid</td>
<td>90</td>
<td>57</td>
<td>75</td>
</tr>
<tr>
<td>Vancomycin</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Ciprofloxacin</td>
<td>63</td>
<td>42</td>
<td>88</td>
</tr>
</tbody>
</table>

Table 1: Antibiotic sensitivity patterns of Staphylococci (% sensitive); selected results

Precise planning of all other stages depends on experience with stage One. In the near future the most important aspect will be the implementation of automatic data transfer from microbiological information system (stage Two), in order to obtain the full benefit of MONI. MONI was programmed in C, C++ and VX-REXX with a state-of-the-art graphical user interface (Presentation Manager, Workplace Shell) for OS/2; the database is implemented in IBM Database 2 for OS/2 (DB 2/2). The prototype of the layer between database and application for the monitoring tasks is designed and implemented using the multitasking and interprocess communication abilities of the OS/2 operating system. The recommended requirements for the use of MONI are a personal computer with a fast Intel Pentium processor, 24 MB RAM, 500 MB hard disk, fast display adapter with a resolution of 1024 x 768, backup and archiving unit (e.g. rewritable optical disk, tape drive), any printer supported by OS/2, IBM OS/2 Warp operating system, and IBM DB 2/2 database.
5. Discussion

MONI is designed as an 'open system' with respect to free definition of terms, a user interface which is not specific to a single hospital, and an interface for automatic data transfer which is as flexible as possible. The system should be evaluated at other hospitals and will be available for other hospitals in the future. Also translation of the user interface into languages other than German is planned.

There were several problems encountered during the planning and realization of MONI. First, there is the problem of recording data. A large hospital has various data sources. To collect all relevant data, various departments have to be contacted or visited. The quality of data is very different and the data items are often inadequately recorded. And, the most serious problem is that some necessary data items are not recorded anywhere. Furthermore, connecting other systems to MONI needs careful planning. A large hospital usually uses a number of information systems which provide different physical (network) and logical (data export) connections. Some systems do not provide any data export function. The availability of such information systems may be a dilemma because some departments do not have any system and it is not known when they will get one. Some systems are planned but not realized, and other systems are currently in realization. Since these problems are currently widespread in our hospital, the planning of automatic data transfer from external systems to MONI is difficult and time consuming. Automatic data transfer saves much in terms of time for data input and of cost of staff for data acquisition; data items are more topical and of better quality. Automatic data transfer is an important prerequisite of an effective monitoring system. Nevertheless, manual data input is of equal importance: It allows stand-alone operation of the system (in case of breakdown of automatic transfer) and is indispensable during implementation of the system or for recording data which is not available by electronic means.

To support collection of distributed clinical data which is not available electronically a pen-based system that assists in mobile data acquisition is under development. A finger print identification system to improve the security of the system will be evaluated in 1997.

6. References


Using Health Indicators to Assess Aboriginal Health in Manitoba

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Abstract

The use of standardized health indicators in the planning and evaluation of community based health care services has gained increasing attention and interest over the past decade. The implementation of the health indicators approach, however, has a number of significant challenges associated with it. These challenges include: 1.) accessing the unaggregated community level data required to construct local indicators; 2.) presenting the indicator data in a manner that is comprehensible and relevant to community members 3.) tying the indicators together with a meaningful and culturally relevant conceptual framework which provides an explanation of how health happens (or doesn't happen) 4.) negotiating the varied and diverse "meanings" that the indicators may have for community members 5.) articulating the implications the indicators have for the planning, implementation and evaluation of community based health programs.

This paper describes the implementation of the Health Indicator approach in Manitoba by the Health Planning and Evaluation Unit, Medical Services Branch. The paper outlines the major data sources accessed, the technical systems built to access, store and analyze health data used in the construction of the indicators, a conceptual framework used to organize the health indicators into a meaningful whole, data presentation and interpretation strategies, a description of the health indicators developed to date and an overview of the feedback received from First Nation Communities and organizations.

1.0 Introduction

The use of standardized health indicators in the planning and evaluation of community based health care services has gained increasing attention and interest over the past decade. This paper describes how the Health Indicator approach was implemented in Manitoba by the Health Programs Directorate, Planning and Evaluation Unit (P+E Unit), Medical Services Branch in support of 61 Manitoba First Nation Communities.

This paper will outline the history and organization of the Health Indicators project, the types of data accessed, the technical systems developed to support the production of Health Indicators, the approach taken to the design and distribution of Health Indicators, the conceptual framework of health used to tie the Health Indicators together into a meaningful whole, initial feedback received from communities on the usefulness of health indicators, and directions for future development.

2.0 History and Organization of the Project

The basis of the current Health Indicators project was envisioned four years ago as a result of the previous conceptual development of a Community Health Status Assessment Tool (CHSAT) for Medical Services Branch [1].

With the implementation of new programs such as the Brighter Futures program as well as the need for a wide range of high quality information for communities relative to the Transfer process, the Director of Health Programs identified and recruited expertise who could further develop and implement the CHSAT.

The current Health Indicators project was developed over the past two years by the Health Programs Directorate, Planning and Evaluation Unit. The Unit consists of the Regional Program Medical Officer, two Data Analysts, along
with a 3/4 time contracted Epidemiologist/Planner. The whole project has been undertaken within existing allocated operating and personnel resources.

The Planning and Evaluation Unit adopted the Health Indicators approach to ensure that when data was distributed to communities, it would be as useful and comprehensible as possible to end-users. Although the project was initially developed by the P+E Unit, it is increasingly becoming a collaborative venture between Medical Services Branch and First Nations. As feedback is received on Health Indicators that have been distributed and as closer relationships are established between MSB and First Nation organizations in preparation for Health Transfer, the project is becoming increasingly responsive and tailored to the needs of First Nations.

3.0 Types of Data Accessed

The first step in implementing the Health Indicators Project was identifying existing sources of data that were available on each First Nation Community in Manitoba. Provincial and National level comparison databases were also identified. As illustrated in figure 1 below, the P+E Unit has identified and is in the process of accessing information from over 20 sources of data.

Figure 1.
In order to bring together the information from all of the databases about a particular community (or a particular group of individuals), the P+E Unit has adopted two strategies to integrate these diverse data sets. These are the implementation of standardized geographic identifiers and standardized personal identifiers.

By coding each database record in the system with a standardized geographic identifier, summary data from each database can be retrieved and linked on a community by community basis, allowing the development of comprehensive community level and Tribal Council level profiles (e.g. all existing data on the community of Split Lake can be brought together). In the system two geographic coding systems have been adopted - Census Sub-Divisions (CSDs) and Postal Codes. By coding each database record with these two geographic identifiers, on-reserve data and other non-Winnipeg data can be retrieved and linked by CSD, and sub-CSD data within the City of Winnipeg can be retrieved and linked by Postal Code or Census Tract.

The second strategy which the P+E Unit is just starting to explore involves coding each database record which refers to an individual person event (e.g. Births, Deaths, Communicable Diseases, Master Client Registry) with a unique personal identifier number. This will allow the linking of the individual level databases on the basis of an individual identifier instead of a geographic identifier. Linking in this way facilitates the identification of health trends within common groups of individuals below or between geographic areas (e.g. common age groups across several communities).

Accessing more than 20+ data sources has been challenging and has involved addressing significant technical, administrative and financial challenges. These have included finding ways of porting data from mainframe computers and central servers onto a PC platform, establishing data sharing arrangements with outside organizations including the Province of Manitoba and several provincial disease registries, and accessing the financial resources required to purchase Census Data, population projections, and geographic conversion files.

4.0 Technical Systems

As illustrated in figure 2 below, the general strategy adopted by the P+E Unit to implement the system has been to a.) access the required data from internal and external sources in electronic format b.) convert this data into a standardized electronic record format c.) build a menued report generator to facilitate easy retrieval and manipulation of data.
The database management system that has been used to accomplish most of these tasks is Epi-Info 6.02. Flat file modification prior to importation into Epi-Info often required the use of a programmable text editor to remove unwanted characters and lines. For this purpose, Wordperfect 5.1 for DOS was used.

When data is first received in an electronic format, it is converted into a standardized Epi-Info .REC file. The data records are standardized on key variables including geography (CSD, postal codes), Band affiliation, date formats etc.

Secondly, a fully menued report generator is built which allows the retrieval of records based on any combination of the variables within the database. Depending on the variable, AND, OR, and NOT searches are available.

Once data has been retrieved it can be used to produce standardized tabular reports, exported to an external program for ad-hoc analysis (e.g. SAS, Spreadsheet, SPSS, NCSS), sent to a GIS (mapping) program, charted, or analyzed within Epi-Info itself (counts, cross-tabs).

The outputs of the system allows the P+E Unit to quickly support a number of organizational business functions. These include supporting the Health Transfer process, planning and evaluating programs, undertaking research projects, responding to ad-hoc requests, and the production of Health Indicators and other custom data products including maps and custom reports. In order to protect the confidentiality of First Nations, data is routinely supplied only to Tribal Councils and other First Nations planning organizations, First Nation Communities, and appropriate Medical Services Branch staff.

5.0 Health Indicators

The main output of the technical systems built by the P+E Unit is the production of Community Health Indicators.

5.1 Definition and History: Community Health Indicators illustrate important and measurable aspects of a community's health and well-being. Health Indicators, as widely accepted measures of health, allow the identification of trends in health status over time and comparison between communities.

The systematic development of population indicators is a fairly recent undertaking. In the United States, population indicators became a major project in the mid-60's and then spread to Europe and Canada in the 1970s, particularly with the development of goal-oriented health policies and the more widespread use of microcomputers [2]. Most recently, Health Status Indicators have been popularized in Canada with the distribution of the "User's Guide to 40 Community Health Indicators" and the recent update of this publication "Health Status Indicators: Definitions and Interpretations" [2]. As well, current efforts in Canada at developing standardized quantitative methodologies for the planning and evaluation of major health reform efforts and healthy community initiatives have maintained widespread interest in the development and use of Health Indicators [3,4,5].

5.2 Design Approach: The approach taken to the design of Health Indicators by the P+E Unit is based on the assumption that the levels of health experienced by a community and the social and physical conditions which give rise to those levels of health are specific to each community. The circumstances which give rise to health conditions in one community are not the same as those operating in another. It is community members themselves who are the real experts about what is specifically going on in their own community and who are best equipped to explain why particular health conditions have arisen.

What this has meant in the design of Health Indicators is that the "meaning" a piece of quantitative data has (e.g. high teen pregnancy rate) must be assigned by members of the community itself. The job of the P+E Unit as "technical" experts is simply to provide appropriate information to a community in a form that is comprehensible and useful, but to leave the tougher job of deciding what the data means for that community and what actions need to be taken to deal with an identified issue up to the community itself. This approach has the potential to mobilize and legitimize a broad range of non-quantitative community "lay" knowledge and experience in the planning process. It also opens the potential for the "official version" of what is going on to be created by community members themselves instead of by external experts operating solely on the basis of quantitative data.
5.3 Lay-out

The P+E Unit has to date designed and distributed 10 Health Indicators. These include:

b. Education Levels
c. Body Mass Index
d. Self Reported Diabetes
e. Birthweight (high and low)
f. Smoking Rates
g. Teen Birth Rates
h. No. of Deaths by Chapter
i. Potential Years of Life Lost by Chapter
j. Infant Mortality

Another 50 Health Indicators have been identified which can be produced on a community by community basis from existing databases.

Each Health Indicator is laid out in a standardized fashion and can act as a stand-alone "fact sheet" in a particular area. In this way, health information provided in the Indicator format can be used to support a wide range of functions including preparation for health transfer, capital planning exercises, community needs assessments and consultations, and preparation of grants and funding proposals.

Each indicator includes the following sections:

a. Graphs: A graphical depiction of the Indicator Data. Whenever possible, Tribal Council, Zone and Provincial comparison data is illustrated.

b. Description: A written description of the depicted data

c. Things to Consider When Interpreting This Indicator: A list of things that community members may want to consider when looking at data for their own Community or Tribal Council area. These considerations are derived from the health literature, from the conclusions of local research projects, and the opinions of key experts and stake-holders. These are offered as suggestions only.

d. Some Possible Health Planning Implications to Consider: list of useful actions suggested by the data that communities may want to consider. Again, these actions are derived from the health literature, from conclusions of local research projects, and the opinions of key experts and stake-holders. These are offered as suggestions only.

e. Community Initiatives Which Have Addressed This Issue: A listing of initiatives undertaken by Aboriginal communities in Manitoba and across North America which have addressed the issues identified by the indicator

f. Data Sources: A precise listing of the sources from which the data for the indicator were derived

g. Data Limitations: A listing of the limitations of the data sources used to construct the indicator
h. Method of Calculation: A detailed description of any calculations or coding systems used in the construction of the indicator

i. Glossary: A definition of terms used in the Indicator by Data Source and Data Type

j. References: A listing of any references cited in the body of the Indicator

k. Data: Spreadsheets of the raw data (as unaggregated as possible, given confidentiality considerations) used to construct the indicator

Health Indicators, in summary, are a vehicle to provide communities with the wide range of information they may find useful in effectively interpreting and making sense of the quantitative health information provided to them.

6.0 Conceptual Framework Of Health Used To Tie Data Together

As the amount of data available for distribution to communities increased over the past two years, it was quickly realized that a conceptual organizing framework was required to tie all of the data sources together. This framework which describes how health happens (or doesn’t happen) was essential to ensure that community members would not become overwhelmed by the sheer volume of information provided to them. By having access to such a framework, they would have a potential tool which describes how each piece of health information can be related to all of the other pieces of health information. For example, when attempting to define community health priorities, community members needed to know how to think about cancer rates, teen pregnancy rates, current and future population structures and education levels all at the same time.

Figure 3.

The framework developed by the P+E Unit is an adaptation of the Determinants of Health framework promoted by the Canadian Institute for Advanced Research (CIAR) [6]. It is based upon extensive research about what keeps people healthy and has been used widely across Canada as basis for health planning and health system reform.
As illustrated in figure 3, this framework suggests that the delivery of Health Care Services is only one of the many factors affecting health. In fact, research compiled by CIAR suggests that health care services, although they consume a large percent of our National and Provincial budgets, have only a very limited impact on our health status. The major "determinants" of health status, the same research suggests, are the social and physical environments in which people live their lives, the biological endowment people are born with, the lifestyles people adopt, and the levels of social support and the quality of life people experience in the communities in which they live.

The CIAR framework has been critiqued for over-simplifying the complexity of the factors which affect health and for failing to place health determinants within a critical social analysis of how wealth and power are distributed within advanced capitalist societies [7]. Despite these limitations the CIAR framework has been adopted because it is a useful starting point for helping communities to think about health in a larger context and for beginning to tie diverse data together. Communities are encouraged to critique the framework, to adapt it to their own needs, and to develop their own frameworks of understanding when possible. Some communities have adapted the traditional medicine wheel as a way of organizing their thoughts about health and well-being.

In practice, each of the indicators is mapped behind the appropriate category in the CIAR framework. For example, population structure, family structure, and education levels are mapped behind Social Environment; smoking rates, teen birth rates, and breastfeeding rates are mapped behind Lifestyle; and mortality, body mass index, and disability rates are mapped behind Health Status.

7.0 Use And Feedback

Although a formal evaluation of the Health Indicators has not yet been undertaken, the P+E Unit has received very positive feedback on them from community members, from consultants assisting with Health Transfer, and from current employees of Medical Services Branch. Generally, end-users have commented that for the first time they are able to use Health Indicators get a sense of the larger "health picture" in communities and of health issues which will emerge over the next several decades.

Two recent Health Transfer proposals prepared by First Nation Communities in Manitoba were able to use the Health Indicators they were supplied with to effectively identify the major health issues which need to be addressed by a restructured First Nation primary care system.

A formal evaluation of the Health Indicators Project and the establishment of on-going methods of feedback from end-users will be implemented this fall and winter.

8.0 Directions For Future Development

Over the next year, the P+E Unit intends to move the project in the following directions:

8.1 Expand No. of Indicators: Increase the number of indicators which are distributed to communities. The P+E Unit currently distributes 10 Health Indicators as well as a variety of unanalyzed data to communities.

8.2 Consolidation and Automation of Data Collection and Technical Systems:

Complete the documentation of data collection and technical systems. This will ensure that the sustainability of the system is not dependent on one individual.

Migration to a more powerful DMBS: Migrate the system to a Windows based database system such as ACCESS, DELPHI or POWERBUILDER. This is essential to increase the speed and the flexibility of the reports which can be produced from the system and to maximize automation of Health Indicator production.

Automation and Expansion of Data Collection: Currently a significant portion of new data (Births, Deaths, Communicable Diseases) are manually entered into the system. By establishing electronic formal data sharing arrangements with the Province of Manitoba and with Provincial Vital Statistics, and by implementing probabilistic data linkage methodology, data accumulation can be automated in these areas. As well, it is expected that electronic access can be expanded to physician and hospital utilization databases.
Linkage to Local Data Systems: If a First Nation Public Health data system such as the Ontario Health Information System is implemented in First Nation Communities in Manitoba then it is essential that links are made to that system.

8.3 Implementation of More Powerful Analytical Approaches: Implement more powerful analytical approaches including expanded use of population projections (i.e. projecting disease rates 20 years into the future), model building using logistic regression techniques, and undertaking focused research projects.

8.4 Transfer to Aboriginal Control: Complete the system documentation and train new staff so the system can be transferred to and maintained by a Manitoba Aboriginal Health Authority.

8.5 Feedback and Evaluation: Establish on-going mechanisms for evaluation of the system.

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Community Health Planning: Determining the Needs of the Community

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Abstract

Provinces across Canada are undergoing a dramatic restructuring of their health systems. One purpose of these efforts is to better ensure that they more effectively meet the health needs of their communities. Often, however, there is no agreed upon method for defining or measuring what those needs are.

The Ontario Ministry of Health recently established a number of Health Intelligence Units throughout the province to address the information requirements of Health Units and District Health Councils. One of these, the Central West Health Information Network, has undertaken the development of a common needs assessment framework to be shared among the members.

The framework builds upon earlier work done by the Canadian Institute for Health Information and by provincial Ministries of Health in Saskatchewan, Alberta and Ontario. It is unique in that it:

1. Integrates needs assessment, priority setting, program planning and evaluation, and quality assurance;
2. incorporates both health status and health systems information; and, 3. demonstrates how a properly conducted needs assessment incorporates standard indicators required for successful decision making in each successive step in the framework.

This paper describes the development rationale for this framework and provides an example of its use.

1.0 Introduction

The Ontario Ministry of Health recently established several Health Intelligence Units throughout the province to address the information requirements of Health Units and District Health Councils. One of these, the Central West Health Planning Information Network (CWHPIN) [1], has undertaken the development of a common needs assessment framework to support the planning initiatives of the fifteen partners in the Network.

Provinces across Canada are undergoing a dramatic restructuring of their health systems. One purpose of these efforts is to better ensure that these systems more effectively meet the health needs of their communities. At least three provinces have moved toward health planning based on needs rather than on past utilization [2-5]. The Ontario Ministry of Health recently published a model for needs/impact-based planning [2] (FIG 1), the first step of which is to "assess needs." Other researchers stress that needs assessment should be the first step in health planning [6-9]. Often however there is no agreed upon method for needs assessment. This paper describes a framework for needs assessment developed for the CWHPIN partners that could also function as the first step in the Ontario needs/impact-based planning model.
2.0 Background for the Health Needs Assessment Framework

2.1 Definition of Health Needs Assessment

Health need has been defined as "a measurable health status deficit or a measurable opportunity to maintain or enhance health" [2] or more simply as "the gap between what is' and what could or should be" [5]. These definitions of need were incorporated into the following definition of health needs assessment and accepted by the CWHPIN Steering Committee: health needs assessment is the process of documenting the current health status and the current health systems operations ('what is') of a target population, and then identifying the required changes in these systems to improve health ('what could or should be'). Although needs assessment models sometimes include priority setting and evaluation [3-4], the definition above does not. Rather, this definition fits with the Ontario needs/impact-based planning model which uses needs assessment as the first step in planning (FIG 1).

Figure 1. Needs/Impact-Based Planning Model

2.2 Definition of Health and the Determinants of Health Model

The terms in the definition of needs assessment require elaboration. Most important, health is defined as: "the extent to which an individual or group is able, on the one hand to develop aspirations and satisfy needs; and, on the other hand, to change or cope with the environment. Health is therefore seen as a resource for everyday life, not the objective of living; it is seen as a positive concept emphasizing social and personal resources, as well as physical capabilities." (WHO, 1986) [10]. The WHO definition of health has been captured by Evans and Stoddart [11] in a determinants of health model of population health. This model emphasizes that while disease and the health care system both affect the health and function of a population, there are other, equally important factors to consider. These include the social environment and the physical environment and also human behavioural and biological responses to disease and to the environment. Indicators of need in the framework will be based on this broad concept of health and health systems, using the determinants of health model.

2.3 Whose Need? - Definitions of Types of Needs

Another area of controversy in needs assessment revolves around "whose need" is considered in the process. Several researchers stress the importance of collecting both quantitative and qualitative data from a variety of sources to ensure that community needs are examined from a variety of perspectives [12,13,14,15]. Royse and Drude [13] and Bradshaw [14] describe four types of needs that should be considered in needs assessment - comparative, normative, expressed and felt. Indicators of normative needs can be seen as the "vision of health" or benchmarks and targets that are described by experts, task forces, commissions, etc. Indicators of comparative needs include information about the determinants of health for the population as they compare with the benchmarks, to other populations and to other areas of health. Expressed needs are described as information about demands or as wants put into action related to health gathered from key informants, consumers, survivors, advocacy groups, government directives, etc. Felt needs are wants related to personal or community visions of health, e.g., "we want to feel safe walking alone at night." The proposed framework is based indicators of need for each of these dimensions.

3. Needs Assessment Framework

In reviewing the needs assessment literature, they identified several steps as critical to some comprehensive needs assessment [2-9]. FIG 2 presents the four steps: 1) define and describe the needs assessment question; 2) decide what information they require; 3) collect the information; 4) analyse the information to categorize level of need. These steps are described in more detail in the next paragraphs using the example of the assessment of injury prevention needs of adolescents and young adults in the Central West region of Ontario.
### Figure 2. Framework for Needs Assessment

| Describe the Area of Assessment | State the research question  
| Define the target population  
| Define area of health  
| Determine level of aggregation of data |
| Decide What Information You Need | Complete literature review  
| Consider types of needs  
| Determine appropriate indicators  
| Consider other planning steps |
| Collect the Information | Use a variety of sources and methods  
| Use CWHPIN/gov't databanks or previous needs assessments  
| Determine what's available/what's missing |
| Analyse the Information to Assess Need | Appropriate breakdowns - age, gender  
| Matrix of issues by types of needs  
| Categorize needs as high/medium/low |

In Central West, the electronic network between the CWHPIN partners and the support from the CWHPIN central office is designed to ease the collection and distribution of information that is essential to the steps in this needs assessment framework [16]. In addition, two working groups established by the CWHPIN Steering Committee - an Indicators Working Group and a Planning Framework Working Group will ensure that the right information is available to partners electronically and that ongoing needs assessment or other planning initiatives are shared among the partners.

### 3.1 Step One - Define and Describe the Needs Assessment Question.

Defining the parameters of the needs assessment as clearly as possible is critical. What is the research question, e.g., what is the need for injury prevention initiatives? Who is your target population - is it the entire population or a defined segment, e.g., 12-24 year old males and females. What level of data are you concerned with - is it regional level vs provincial or planning district, e.g., Central West Ontario (Brantford, Haldimand-Norfolk, Halton, Hamilton-Wentworth, Niagara, Waterloo, Wellington-Dufferin planning districts). How is your topic defined - what is included and excluded in your assessment, e.g., both unintentional and intentional injury by cause of injury will be included as described in International Classification of Diseases 9-Codes, External Causes.

### 3.2 Step Two - Decide What Information Is Required

Completion of a comprehensive review of the published and unpublished literature on the topic is the suggested starting point for this step in needs assessment [2]. Such a review will help to identify possible indicators for the types of need (comparative, normative, expressed and felt) and determinants of health. At this point a matrix (type of need vs determinant of health) is drawn up to structure the required information. For example, research may suggest
the use of the crash involvement rate of young drivers compared with other age groups as an indicator of comparative need in the human response to the environment domain.

Another point to consider in this step is that the needs assessment will be completed as part of an overall planning process. Thus, it is necessary think ahead to the information required for other steps in the process. What outcome measures will be used for future evaluation? What priority setting method will be used? It is critical to use indicators in the needs assessment stage that will also inform the subsequent stages of planning. For example, if it is anticipated that a reduction in motor vehicle crash involvement of adolescents and young adults will be identified as a goal (outcome measure) for injury prevention in the region, then data about current levels should be collected. This data will also contribute to the assessment of "comparative needs" for injury prevention.

Feather, et al. [5] also recommend a focus on gathering information about the problem or need rather than about the solution (services). The optimal solution to the problem is not necessarily a "service" but may be some form of community action to remove or change the root cause of the problem. For example, it is more important to collect information on the factors correlated with high crash involvement in young drivers rather than collecting information about the availability of drivers' education programs since the most effective way to prevent motor vehicle crashes among adolescents may be to increase the age of licensing rather than to provide more drivers education programs. The Indicator's Working Group of CWHPIN is available to the partners in Central West as a resource to identify relevant indicators for this step of the needs assessment. This group is also developing a searchable database of regional resources relevant to health planning which will support this step in needs assessment.

3.3 Step Three - Collect the Information

The use of multiple methods of data collection has been stressed as critical to a comprehensive needs assessment [13,15,17-19.] and is important to ensure that the perspectives of community, consumers, providers, and funders are included. Brazil and Anderson [15] recommend the use of a combination of techniques including population statistics, utilization statistics, survey methods and structured groups. At this step it is important to be aware of data sources that are already available since it is time-consuming and expensive to collect new information. In Ontario there has been considerable progress in establishing a data warehouse [16] which integrates several data sources such as census, health care system use, morbidity and mortality statistics, and home care use which are available at the regional level. Other sources which are specific to the topic and available at the level of aggregation required should also be explored, e.g., Ontario Trauma Registry, regional/provincial police databanks. The feedback from community forums, public meetings, advocacy groups, task force reports (e.g.,[20,21]) and the results of needs assessment surveys and other health surveys (e.g., Ontario Health Survey) should be examined for relevance.

As mentioned above, CWHPIN is developing a databank of available resources in Central West which will include statistical databases and regional health-related reports and documents. This database will be available from the CWHPIN home page on the Internet. The CWHPIN Planning Framework Working Group has also initiated a World Wide Web site with links to resources to support needs assessment information collection. Completed needs assessments in the region will be posted to this site for use by other partners.

3.4 Step Four - Analyse the Information

This stage must answer the question "is there a gap between what is and what could, or should be" and "how big is this gap." To do this, the indicators collected in Step Three are analysed to determine which issues represent high, medium, or low needs. The analysis will depend on the type of information collected but may include secondary analyses of existing survey results, determining and ranking morbidity and mortality rates, comparison of risk behaviours with benchmarks, collating information from key informants and community forums, etc. The drawbacks to each collection method should be considered in interpreting the data [7-9,20].

Bradshaw [14] recommends tallying across the four types of needs to rank the identified needs. The needs list for injury prevention is ordered according to this tally (Table 3), i.e., motor vehicle crash injury to drivers and passengers scored 12 and is listed first. However it is important to present the information for each of the types of need rather than the total score for each cause of injury. For example in Table 3, suicide and assault/violence have the same total across the four needs and therefore have equal ranking on the needs list. But there is a large
discrepancy in each type of need score for these two causes with the felt and expressed need for violence/assault prevention much higher than that for suicide while the opposite is true for comparative and normative needs. This may be an area for which the community perception of the problem is at odds with the statistics, for example the public may be unaware of the suicide mortality rate compared with the rate for homicide. Or it may indicate that the community is ready to mobilize around violence prevention but not around suicide prevention. It is critical to note this discrepancy as it will be useful in the priority setting and the action plan steps of the planning process.

Table 3. Example of Analysis of Information Collected in Needs Assessment

<table>
<thead>
<tr>
<th>Cause of Injury</th>
<th>Expressed Need</th>
<th>Comparative Need</th>
<th>Felt Need</th>
<th>Normative Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor Vehicle Crash</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drivers</td>
<td>xxx</td>
<td>xxx</td>
<td>xxx</td>
<td>xxx</td>
</tr>
<tr>
<td>Passengers</td>
<td>xxx</td>
<td>xxx</td>
<td>xxx</td>
<td>xxx</td>
</tr>
<tr>
<td>Suicide</td>
<td>xxx</td>
<td>xxx</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Assault/Homicide</td>
<td>x</td>
<td>x</td>
<td>xxx</td>
<td>xxx</td>
</tr>
<tr>
<td>Sports Injury</td>
<td>xx</td>
<td>xx</td>
<td>xx</td>
<td>x</td>
</tr>
<tr>
<td>Motor Vehicle Crash</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cyclists</td>
<td>x</td>
<td>x</td>
<td>xx</td>
<td>xx</td>
</tr>
<tr>
<td>Falls</td>
<td>xx</td>
<td>x</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Burns</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

x = information collected indicates low need; xx = medium need; xxx = high need

4.0 Summary

Comprehensive needs assessments are recognized as critical first steps in restructuring regional health systems. The needs assessment framework presented above provides a common tool for use by all the public health units and district health councils in the Central West region of Ontario. The steps in the assessment require a considerable resource investment but the electronic network among the CWHPIN partners should result in efficiencies in completing present and future needs assessments. The results of improved needs assessment and planning should ultimately be reflected in improved health outcomes for the region's population.

References


Expert Systems

Chair: Jochen Moehr
Temporal Reasoning and Learning from Cases for Patients Follow-up

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Keywords: case-based reasoning, machine learning, temporal reasoning

Abstract

The system presented in this paper is a case-based reasoning (CBR) system capable to adapt to the different cognitive tasks performed by the medical experts of a specialized domain. It provides assistance to the experts for diagnosis, treatment planning, follow-up and clinical research assistance. For long-term follow-up, as well as for the other tasks, a temporal representation is needed for the patients cases. Both the case memory and the reasoning process have been improved to handle temporal data. The general reasoning cycle starts with an abstraction step in which the raw, time-stamped, data are transformed into interval-bound data, by a temporal abstraction process. The following reasoning steps are the classical CBR steps: retrieve, reuse, revise and retain. Nevertheless, temporal reasoning is taken into account in each of them, although the system is able to reason both from temporal data and from time-independent data. Moreover, it adapts to the granularity of the time represented. The memory the system is organized around trends learnt from the cases by temporal concept learning during the retain step, and this permits the system to provide synthetic information about the patients, thus assisting clinical research.

1. INTRODUCTION

Case-based reasoning [7] is an artificial intelligence methodology for the processing of empirical knowledge. It reasons from cases, which are sets of empirical data, such as patients cases in a medical domain. Previously processed cases are stored in a case-base, or memory, and used by such a system to process new cases. The processing of a new case uses one or several memorized cases similar to the new case. It reuses these similar cases in order to propose a processing for the new case. In particular, the organization and the composition of the memory, giving it the ability to be accessed and updated constantly during the reasoning process, are a key issue for a case-based reasoning system. MNAOMIA is a case-based reasoner applied to the domain of eating disorders in psychiatry. Its aim is to provide assistance to experts in the different cognitive tasks they perform, namely diagnosis, treatment planning, patients follow-up and clinical research [c]. For such a task as follow-up, time processing is an essential component of the MNAOMIA system. This task has been chosen for this article among the several tasks performed to further explain the handling of time in MNAOMIA. In the second section, an overview of the MNAOMIA case-based reasoner is given. Time representation is proposed in the third section. Following, temporal learning, in the fourth section, and temporal reasoning, in the fifth section, are presented. They are followed by the conclusion.

2. PRESENTATION OF MNAOMIA

MNAOMIA is a case-based reasoning system the aim of which is to realize a complete reasoning system taking advantage both from experimental and from theoretical knowledge in order to perform different cognitive tasks [2]. It can provide assistance to experts in their realization of these tasks. In complex domains, such as medical domains, it proves necessary for case-based reasoning systems both to be able to perform several cognitive tasks, such as diagnosis, treatment and clinical research, and to take advantage both from experimental and from theoretical knowledge, because this is the way the experts reason. The same clinicians perform diagnosis and clinical research. They start using mostly theoretical knowledge, then they learn through practice. They always keep, and increase, these two types of knowledge and take advantage the most from them depending on the cognitive tasks they perform. MNAOMIA has the same capabilities.

The general reasoning cycle of case-based reasoning, inspired by Aamodt and Plaza [1] (see Figure 1), starts with the input of a new case to the system, which is a set of empirical data from a certain application domain. In the Abstract
step, this initial case is abstracted into an abstract case, during which the indices of the case are calculated so that it can be compared with the cases in memory. Following, in the Retrieve step, the memory is searched for similar cases to this new case, and a set of these most similar cases is extracted. This set is often ranked by decreasing similarity. In the Reuse step, either the best case or a sub-set of the extracted cases are chosen to be reused in order to propose a processing for the new case: an adaptation in problem-solving or the construction of an argumentation in interpretation. This proposed case is then tried in the application domain, or in a simulation, and results from this experimentation are given back to the system. In the Revise step, the proposed case is repaired and is ready to be added to the memory, in the Retain step.

Figure 1. The reasoning cycle of case-based reasoning.

In the case-based reasoning paradigm, a system Scbr performs a reasoning R, including a set L of machine learning techniques, on a memory M in order to perform a set of cognitive tasks T:

\[
\text{Scbr} = \langle R, M, T \rangle, \text{ with } R \text{ includes } L
\]  

The reasoning process follows the different steps represented on Figure 1. The memory M is a network of cases ci and categories Cj linked by relationships ik, also called indexes, i.e. is-more-specific-than between categories, is-an-instance-of between categories and cases:

\[
M = (C, K, I) \text{ where } C = \{..Cj...\},
K = \{..ci...\},
I = \{..ik(n1,n2)...\}, \text{ with } n1,n2 \in (C \cup K).
\]

The instantiations of the Scbr paradigm (1) in MNAOMIA are:

- **Reasoning R**: the different reasoning steps in Figure 1.
- **Memory M**: it is composed of several kinds of cases (patients, staff, control subjects), and categories (prototypes given by the experts or learnt from the cases, concepts learnt from the cases).
- **Tasks T**: it comprises the set T = \{diagnosis, treatment-planning, follow-up\} and a knowledge discovery task clinical-research.
3. TIME REPRESENTATION

Each entity E in memory is a conjunction of representation elements Eli, of two types: attributes Att associated with values Val describing static knowledge, and relations Rel between two entities in memory Ent1 and Ent2. The latter will not be presented here (see [3]).

\[ E = Eli \]  
with:

\[ Eli = < \text{Time}_{i,s}, \text{Time}_{i,f}, \text{Att}, \text{Val}> \]

Associated with each Att is a function which returns the range of this parameter type, range(Att) (for example range(Calories) = 100kcal). Temporal values Time_{i,s} (starting time) and Time_{i,f} (finishing time) can be associated with each element of representation Eli, whether attribute or relation, and can be of several granularities (second, minute, ...). Depending on time, three types of element of representation are defined (they are given here for attributes, but they also exist for relations):

A **time-independent** attribute-value pair (such as the patient name):

\[ Eli = < \text{Att}, \text{Val}> \]  

A time can be associated to it, for example the date when this data element has been recorded, but it is not necessary.

A **time-point** attached to an attribute-value pair corresponds to a qualitative value (such as high blood-pressure at arrival time) or to a discrete quantitative value (such as weight equals 37.8 kg at arrival date):

\[ Eli = < t_i, \text{Att}, \text{Val}> \]

A **time-interval** attached to an attribute-value pair corresponds to a qualitative value or a discrete quantitative value constant over a time interval (such as high blood-pressure from week 2 to week 3, result of a test 125 from month 1 to month 2), or the evolution of a continuous qualitative value over a time interval (such as weight 39kg from day 2 to day 4):

\[ Eli = < t_i,s, t_i,f, \text{Att}, \text{Fi}(t_i,s, t_i,f)> \]

where \( t_i,s \) is the start and \( t_i,f \) is the end of the interval. The attribute value \( \text{Fi}(t_i,s, t_i,f) \) is produced by a function on the set of parameter values covered by the time interval. For a discrete quantitative value, the value chosen is the speed of the parameter over the interval, which is calculated by an integral if the value is continuous.

4. TEMPORAL LEARNING

During the Retain step, also called Memorization, MNAOMIA performs an incremental concept learning. The original algorithm used, which has close roots with the case-based reasoning methodology, is the UNIMEM algorithm [8]. It has been modified, particularly to handle time processing. Here, concepts are called trends because they represent frequently occurring temporal patterns found in cases.

Let a new case Case be presented to the system. The search through the memory for the most similar memorized cases, which is the Retrieve step, starts from the root of the hierarchy of trends built by this algorithm. So the search starts by Search(Root ase).

Search(Trend, Case)  
result := {}  
for all representation elements in Case  
if match(Trend.Element, Case.Element)  
then POS := POS + 1  
ext else NEG := NEG + 1  
if POS - NEG < threshold  
then remove the element from the Trend representation  
if Trend is empty  
then suppress the Trend from the Memory  
link its sub-trends to its super-trends in the hierarchy (fusion)
if there is at least one contradictory representation element between Trend and Case then return Nil
else for all Trend sub-trends
    newresult := Search(sub-trend, unmatched elements in Case)
    if newresult <> Nil then result := result + newresult
    if result <> {} then return result
    else return {Trend}

NEG and POS are discrimination variables associated to each representation element in a trend that permit the pruning of the trends learnt. The pruning of trends and attributes will eventually remove any redundant trends. The sub-trends are the trends led to the current trend by is-more-specific-than relations. This search returns a set of the most specific trends under which the new case could be indexed. The second part of the UNIMEM algorithm Insert(Trend, Case) deals with the construction of new ends. It is called to insert the new case in the memory during the Retain step at all trends retrieved by Search. Before inserting a case, the hierarchy of trends is revised, thus improving the original UNIMEM [8] algorithm drawback of being too sensitive to the order of presentation of the cases (see [4] for more details).

Adjust(Root, Case)
Insert(Trend, Case)
UnMatched := Elements of the Case not explained by the Trend Elements for all entities e-i indexed under the Concept
    nb := number of successful match(Unmatched.Element, e-i.Element)
    if nb > threshold
    then
        create a new sub-trend Tn of Trend with these successful matches
        index Case under Tn
        index e-i under Tn
        remove e-i from the entities indexed under Trend
        if Case has not yet been indexed under a new sub-trend of Trend
        then index Case under Trend

Both algorithms rely on matching predicates, the definition of which involves the temporal representation of the cases, and of the trends learnt from them. Let \( C = \neg C \) \( E_iC \) and \( T = \neg T \) \( E_iT \) be the representations of the case \( C \) and the trend \( T \). An element in the trend representation \( E_iT \) and an element in the case representation \( E_iC \) match if all their components match. Three main types of element (and their generalizations) have been defined for a case, and so a matching predicate must be defined for each of these:

\[
\text{match}(C, T) \iff V iT, V iC [\text{match}(E_iC, E_iT)]
\]

Depending on the type of the representation element, the match predicate takes the following forms: match-indep(\( E_iC, E_iT \)) matches two time-independent elements (4):

\[
\text{match-indep}(E_iC, E_iT) \iff V iT, E iC [(\text{Att}(C) = \text{Att}(T) \land (\text{Val}(C) = \text{Val}(T))]
\]

match-point(\( E_iC, E_iT \)) matches two time-point elements (5):

\[
\text{match-point}(E_iC, E_iT) \iff V iT, E iC [(\text{Att}(C) = \text{Att}(T) \land (\text{Val}(C) in (\text{range}(E_iT)))] (\text{Att}(T) \land (\text{range}(E_iT))]
\]

Each time-point \( t \) has a \((\min, \max)\) range for matching. This depends on the time type \((\text{Year}, \text{Month}, \ldots)\) and the \text{Att}, and is returned by the function \text{timerange}(\text{Att}). The time-point range is \((\min = t_i - \text{timerange}(\text{Att}), \max = t_i + \text{timerange}(\text{Att}))\). In addition each attribute \text{Att} has a \((\min, \max)\) range for matching \((\min = \text{val} - \text{range}(\text{Att}), \max = \text{val} + \text{range}(\text{Att}))\).

match-interval(\( E_iC, E_iT \)) matches two time-interval elements (6):

\[
\text{match-interval}(E_iC, E_iT) \iff V iT, E iC [(\text{ti}(C, s, t) \text{ during } (t, f )] (\text{Att}(C) = \text{Att}(T) \land (\text{Fi}(C, t, s, t) \text{ in } (\text{range}(E_iT), \text{Fi}(T, t, s, t) + \text{range}(E_iT))]
\]
Also, trends are linked to other trends by the relations *is-more-specific-than* (and its reverse relation). This relation permits the automatic building of a hierarchy of trends by the *Insert* algorithm. Figure 2 shows that the trends in memory may contain time-independent elements, time-point elements and time-interval elements. The hierarchies built are dependent upon the task performed, such as here diagnosis, or treatment planning.

5. TEMPORAL REASONING

A case used by the follow-up task is characterized by the large amount of data available. For this task, data abstraction is necessary to get both an accurate and efficient processing. The main steps in the reasoning process are:

1. **Abstract**

An initial patient case is a conjunction of representation elements attached to time or independent from time, such as *(the bmi is a special evaluation for the weight)*:

<table>
<thead>
<tr>
<th>Case1=</th>
<th>Surname</th>
<th>Catherine</th>
<th>Diagnosis</th>
<th>Anorexia-nervosa</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21/06/95</td>
<td>Bmi</td>
<td>15.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>21/06/95</td>
<td>Weight</td>
<td>38.9kg</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22/06/96</td>
<td>Weight</td>
<td>38.5kg</td>
<td></td>
</tr>
<tr>
<td></td>
<td>24/06/96</td>
<td>Weight</td>
<td>39.0kg</td>
<td></td>
</tr>
<tr>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td></td>
</tr>
</tbody>
</table>

The attributes describing a patient are various, and cover all the domains of the psychopathology. From these data, the main facts in the patient evolution are summarized. A *FindIntervals* algorithm abstracts intervals from this representation, for all attributes having an evolution, and attaches to each interval a value within the set {Decreasing-very-much, Decreasing, Stable, Increasing, Increasing-very-much}. For data not evolving through time, the abstraction algorithm transforms for instance numerically into qualitative values within the set {Very-low, Low, Normal, High, Very-high}:
2. Retrieve

The abstracted case is then matched against the trends in memory by the Search algorithm. The case is first matched with the most general trends, and following with more and more specific trends. The result returned by this algorithm is a set of trends (one of which being possibly time-independent). Under these trends, entities are indexed by is-an-instance-of relations. These entities are generally cases or prototypes. They are ranked by a similarity measure (see [3]), which permits to choose the one which are the most similar to the new case.

The temporal aspect of the patients follow-up will be here to look for the most important trends detected by the system, and for the cases indexed under these. Since the time span extends a lot, an ExtendedSearch algorithm is substituted to the Search algorithm. Instead of searching for matching trends where the intervals are separated by a timerange(Att) temporal distance, the successive possible distances will be tried, from the lowerbound of the interval, to its upperbound (these are associated to each interval during the incremental concept learning). The ExtendedSearch algorithm is as the Search algorithm, except that it uses an extendedMatch predicate for matching representation elements E₁₁ and E₁₂ containing intervals.

```
extendedMatch(E₁₁, E₁₂)
  ts := lb₁
  delta := t₁.f - t₁.s
  match := false
  nbmatch := 0
  until ts >= ub₁
    t₁.s := ts
    t₁.f := ts + delta
    if match-interval(E₁₁, E₁₂)
      then nbmatch := nbmatch + 1
      ts := ts + delta
    if nbmatch > 0
      then match := true
  return match
```

This extended matching is close to that of some well known temporal reasoning systems [5,6,9].

3. Reuse

The reuse is an adaptation, and starts from the different cases retrieved thanks to the extended matching predicate. It produces a follow-up protocol, reusing the elements found in the most similar extracted case, after adapting them to the new patient his proposed processing can be executed, and its results analyzed in the next step.

4. Revise

The effects from the processing of the new case are evaluated, and the system corrects whatever unsatisfying effect.

5. Retain

The algorithm for retaining a new, revised case at a given trend is the Insert algorithm given earlier.
6. CONCLUSION

Among the different tasks performed, patients follow-up required to grant MNAOMIA with an efficient time processing. This article has presented a temporal representation for the cases, permitting the system to organize its case-base around hierarchies trends automatically learnt by incremental concept learning. Temporal abstraction facilitates the recognition of the similarity between cases, and is the key mechanism both to the knowledge representation and to the reasoning process. This approach is table for any domain where many data evolving through time are available, and we are currently applying MNAOMIA to other domains than eating disorders.

7. REFERENCES


ITCH '96: Expert Systems

Development, Validation, and Evaluation of an Expert System to Provide Decision Support for Nursing Diagnosis in Aged Care.

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Keywords: expert systems, nursing diagnosis, evaluation

Abstract:

Proponents of expert systems have made a wide variety of claims about the potential benefits nurses would derive from their use, but no evidence of these claims being supported by substantive research can be found. Utilising literature on the nursing diagnosis taxonomy developed by the North American Nursing Diagnosis Association (NANDA) this project has developed a prototype expert system to provide decision support for nursing diagnoses in aged care settings. The prototype expert system was evaluated in aged care settings and, based on user feedback, a new Windows version representing the complete diagnostic taxonomy is being written. The utility of this expert system as a clinical decision support tool will then be evaluated by registered nurses within aged care. This project also aims to provide guidelines for developing expert systems for clinical practice.

Introduction:

An expert system is a computer program which models expertise, rules or heuristics, and acts as an expert interpreter of data within a narrow domain (Benfer, Brent and Furbee, 1991). Within nursing literature, proponents of expert systems have made a variety of claims about the potential benefits of using such software. Anticipated benefits include provision of consistency of decision making, increasing productivity, preservation and expansion of expertise, provision of a better understanding of problems, and staff development (Schank, Doney & Seizyk, 1988). There have also been suggestions that expert systems may offer a more efficient and cost effective approach to clinical decision making and greater flexibility in allocating resources (Petrucci & Petrucci, 1991); and, improve the consistency and quality of nursing decisions as well as decreasing the possibility of wrong decisions (Brennan, 1988). However, no attempt to formally evaluate an expert system within clinical practice can be identified, and in the absence of such evaluation any debate of the relative merits of such software remains largely conjectural.

A particularly striking example of the chasm between the anticipated promise of expert systems, and subsequent failure to deliver this promise in clinical practice was provided by Jones (1992a), who, after undertaking a literature review relating to expert systems in nursing, found 86 published papers on the topic. On writing to the principal author of all these papers he failed to identify a single expert system in either regular or occasional use within nursing, for educational, practice or management purposes. Four years later Jones (1996) asserted that this chasm remains, which is a perplexing situation as rules based problems [such as nursing diagnoses] are thought to be particularly suited to the expert systems approach (Feigenbaum, 1977).

A current extensive literature review by the author, using both healthcare and computing databases elicited several articles and papers on expert systems in nursing, but still yielded none dealing with implementation and evaluation of such systems in nursing practice. The issues addressed include knowledge acquisition (Bobis and Bachland, 1992), relative merits of rules based versus case based reasoning (Bradburn and Zeleznikow, 1993), and rules processing within inference engines (Budiardjo, Grzymala-Busse, and Woolery, 1991; Harding and Redmond, 1996).
The Research Objective:

The problems encountered by practitioners when using nursing diagnoses have been reported by several authors who indicate that nurses appear to successfully collect client data, but often fail to properly examine the relationships, so that often they make poor judgments or do not arrive at appropriate diagnostic conclusions (Kelly 1966; Grier 1981; Field 1983; Chou 1995). This project seeks to develop and validate an expert system, and assess its utility in providing decision support to nurses undertaking client assessment within aged care settings. Importantly, an expert system, in this research context, reminds a nurse of options or issues to consider when determining nursing diagnoses and planning subsequent client care. This is quite distinct from a decision making program which allows users to make decisions beyond their level of training. (Widman, 1995).

The overall utility of an expert system, as perceived by users, is the result of complex interaction between the user and the computer program. Issues such as interface standards, ease of use, completeness and accuracy of conclusions, modifiability of data, user characteristics and impact on work practices have been demonstrated to influence user evaluations, and therefore should be considered when constructing an evaluation model (Adelman, 1992; Powrie, Koch and Fernandez 1993; Chou, 1995).

The first phase of this research project is now complete. This phase sought to develop a prototype expert system, which contained only a subset of the accepted NANDA taxonomy. This prototype expert system was written in PROLOG and piloted in several aged care facilities throughout the Melbourne metropolitan area by Chou (1995) whose findings clearly identified both strengths of the expert system approach to care planning and issues which require to be addressed in subsequent iterations of the program. Users (n=27) commented favourably on the user interface, finding it easy to use, with an easily understood structure and providing an easy method of entering and modifying client data. Several shortcomings were however identified, which included the limited ability to modify client goals and interventions, care plans produced did not comply with the format used in the specific sites used. Users also requested a standard Windows type interface with more flexibility of file management operations such as saving and printing. Based on these responses the next phases of this project will create an expert system which incorporates the complete NANDA taxonomy, and addresses much of the user feedback elicited by Chou (1995) and then assess its utility in clinical practice.

Using the expert system:

A variety of nomenclature exists for describing the types of knowledge represented within expert systems (Benfer et al 1991) however the lack of consistency in the use of terms is potentially confusing. Within this project, knowledge is described as either procedural or contextual. Procedural knowledge is the taxonomic rules structure developed from NANDA literature which reflects the data relationships which are used to reach conclusions. This taxonomic structure is reviewed annually by a panel of international expert diagnosticians appointed by NANDA.

Contextual knowledge is provided by nurses using the expert system, and may be illustrated by their decision to reject suggested diagnoses, or modify suggested goals or interventions. Such decisions are based on nurses’ professional judgments of what is relevant for individual clients or care strategies which have been known to be successful for previous clients. Thus the expert system may constantly evolve as the context of care may always be included in care plans which are developed.

The specific process of using the expert system to create a care plan is as follows. Nurses enter client data which they have elicited from or about the client being assessed. Possible diagnostic conclusions are then suggested by the expert system. These diagnoses are presented in order of likelihood, a hierarchy which is determined by the number of defining characteristics, thus the diagnoses with most data are presented first. The data utilised to substantiate each diagnosis are also presented and the nurse must then choose which diagnoses may be deemed relevant for the individual client being assessed, and reject those which are not applicable.

In addition possible goals and interventions which may be considered to resolve the identified diagnoses are also suggested. Modification of these data allows the nurse to identify strategies to deal with these diagnoses, before developing or implementing a plan of care. The nurse can also decide whether goals and interventions should apply only to the client under consideration or be suggested for all subsequent clients with this particular diagnosis. Thus
contextual knowledge may be included on an ongoing basis by the nurses and allow care plans, relevant to specific clients within aged care to be developed. This ability to include contextual knowledge on an ongoing basis was not present in the prototype expert system evaluated by Chou (1995) and was cited as a major shortcoming by the nurses who used the software. Thus nurses using the expert system when planning care may access the experience of expert diagnosticians while still retaining control over the clinical decision making process by using their professional judgment to modify all care plans prior to implementation.

Ongoing work:

Development of the complete expert system is now under way. Expert systems have traditionally been written using special programming languages such as LISP or PROLOG, but are increasingly written using an expert system shell, a program which allows the expert system to be constructed without the necessity for programming expertise (Benfer et al 1991; Jones, 1992b). The latter approach will be adopted using a shell called ExShell, which will allow the authors to represent within the expert system all the diagnoses accepted within the current NANDA taxonomy along with their defining characteristics. The necessary data for a complete knowledge base will be elicited from published literature e.g. Kim, McFarland and McLane (1995), Gordon (1995), and the regularly published NANDA conference proceedings, which serve to identify the evolving taxonomic structure and related defining characteristics. The use of literature overcomes difficulties traditionally associated with the acquisition of knowledge from individual experts, who may have difficulties in articulating the processes used in problem solving, have idiosyncratic world views, or ignore their own rules (Waterman and Hayes-Roth, 1978; Benfer et al 1991). Using the available NANDA literature as the means of constructing the knowledge base also allows a consensus view of international experts to be obtained, as NANDA updates the taxonomy on an annual basis to reflect the decisions of a panel of expert diagnosticians.

In addition it is thought to be important that the expert system also has the ability to explain the rationale for arriving at a particular conclusion, in order to make clear the data relationships used in the reasoning process and also to monitor its own performance by identifying rules which are used frequently and those which have never been used. This latter exteriorisation of the knowledge used and redundancies within the expert system are described as “metaknowledge” (Lenat, Davis, Doyle, Geneserth, Goldstein and Schrobe 1983). In a nursing diagnosis context this feature should prove useful, to both individual nurses and NANDA, by providing an automatic audit trail of client problems encountered and solutions implemented within a specific care context.

Several iterative cycles and refinements of the knowledge base are envisaged to ensure reliability of the expert system. ExShell includes rules tracing, which allows the researcher to see which conclusions are activated by individually selected defining characteristics or conversely what data are required to substantiate a diagnosis. This will be accomplished by individually selecting defining characteristics and checking the diagnostic conclusions reached against those proposed within the NANDA literature. The program will only be deemed reliable when those diagnostic conclusions substantiated by NANDA literature are derived from the data which are input and any erroneous or aberrant conclusions are no longer evident. When such conclusions are identified the data editor within ExShell will be used to refine the procedural rules.

Using purposive sampling a panel of experts (n=10) will be established. Using test cases of real client data proposed by these experts, validity testing will be undertaken to establish whether or not the expert system consistently reaches diagnostic conclusions with which the panel agrees. In the case of diagnostic conclusions of the expert system failing to agree with those of the experts the rules base will require further refinement until accord with experts is reached (Benfer et al 1991).

Prior to implementation of the expert system in the clinical area pre-test data on existing diagnostic and care planning processes will be obtained from RNs (n=80) using a structured interview technique. Following training in use of the expert system and three months experience of using the expert system in clinical practice the RNs will be again interviewed individually and asked to rate the expert system performance on a variety of parameters including interface standards, ease of use, completeness and accuracy of conclusions, modifiability of data, and impact on work practices which collectively contribute to an overall utility score. Using multiple regression these sub scores can individually be examined to identify strengths and weaknesses of various parameters of the expert system approach to nursing diagnoses. This is the statistical analysis of choice as the research question posed is one where multiple independent variables may mutually and simultaneously influence a dependent variable (utility score).
Additionally pre and post test data will be analysed using ANOVA. Data from these analyses can in turn form the basis of guidelines for subsequent development or evaluation guidelines for expert systems in healthcare.

All developmental work completed by the time of presentation will be presented.

References


Jones, B. Personal communication, 1996.


Knowledge-Based Interpretation of Serologic Tests for Hepatitis in WWW

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Keywords: expert system, World Wide Web, hepatitis serology, HEPAXPERT-III.

Abstract

HEPAXPERT is a knowledge-based system that interprets the results of routine serologic tests for infection with hepatitis A and B viruses. The following tests are included: hepatitis A virus anti-bodies (anti-HAV), IgM antibodies to the hepatitis A virus (IgM anti-HAV), hepatitis A virus (HAV) in stool, hepatitis B surface antigen (HBsAg) and antibodies (qualitative anti-HBs, quantitative anti-HBs titre), antibodies to hepatitis B core antigen (anti-HBc and IgM anti-HBc), and hepatitis B envelope antigen (HBeAg) and antibodies (anti-HBe).

HEPAXPERT/WWW - an implementation of HEPAXPERT-III for WWW - can be reached by URL http://www.med-expert.co.at/hepax_ of the World Wide Web. After selecting HEPAXPERT/WWW, serologic test results can be entered and will be transferred as an e-mail message for subsequent interpretation which is done off-line with HEPAXPERT-III. The textual interpretation is sent back via e-mail.

Each qualitative test for hepatitis A and B antibodies and antigens may produce one of four possible results: positive, negative, borderline, and not tested. To cover the resulting 64 (A) and 24,576 (B) combinations of findings, the knowledge base of HEPAXPERT/WWW contains 16 rules for hepatitis A and 131 rules for hepatitis B serology interpretation. This basic knowledge is structured such that all possible combinations of findings can be interpreted and there is no overlap in the premises underlying the rules.

The reports that the system automatically generates include (a) the transferred results of the tests, (b) a detailed analysis of the results, including virus exposure, immunity, stage of illness, prognosis, infectiousness, and vaccination recommendation, and (c) optional: an ID to distinguish the origin of the interpretation requests.

1. Introduction

HEPAXPERT/WWW is an implementation of HEPAXPERT-III [1] for WWW. HEPAXPERT-III - the successor of HEPAXPERT-I [2, 3] and HEPAXPERT-II [4, 5] - is an expert system that interprets the results of qualitative and quantitative routine serologic tests for infection with hepatitis A and B. The tests measure antibody to the hepatitis A virus (anti-HAV), IgM antibody to hepatitis A virus (IgM anti-HAV), hepatitis A virus (HAV) in the stool, hepatitis B surface antigen (HBsAg) and antibody (both qualitative anti-HBs and quantitative anti-HBs titre), antibodies to hepatitis B core antigen (anti-HBc and IgM anti-HBc), and hepatitis B envelope antigen (HBeAg) and antibody (anti-HBe). The HEPAXPERT-III system automatically provides and interprets the result of these tests, without the use of additional biochemical or clinical data, and thus helps physicians to understand complex serologic findings.

2. Methods

Each qualitative test for hepatitis A and B antibodies and antigens may produce one of four possible results: 'positive', 'negative', 'borderline', or 'not tested'. The quantitative anti-HBs titre test can either have the result 'not tested' or may fall into one of the following five titre ranges: '0', '[1,10]', '[11,34]', '[35,79]', and '[80,...]'. Because there are three qualitative tests for hepatitis A (anti-HAV, IgM anti-HAV, and HAV in the stool) and six qualitative tests plus one quantitative test for hepatitis B (HBsAg, anti-HBs, anti-HBc, IgM anti-HBc, HBeAg, anti-HBe, and anti-HBs titre), there are 64 (4 to the power of 3) possible combinations of findings for hepatitis A, and 24,576 (4 to
the power of $6 \times 6$ possible combinations for hepatitis B serology test results. With HEPAXPERT-III, each combination is associated with one specific textual interpretation.

To deal with the 64 and 24,576 possible combinations of findings, the knowledge base of HEPAXPERT-III contains 16 rules for hepatitis A and 131 rules for hepatitis B interpretation. These rules were defined for various purposes. For hepatitis A, we developed 13 rules to interpret the given combination of test results (interpretation step) and three rules to add specific advice, if necessary (completion step). In the more complex situation of hepatitis B, 11 rules combine the qualitative anti-HBs and the quantitative anti-HBs titre test results (preprocessing step), 115 rules establish an interpretation of the then given combination of findings (interpretation step), and five rules are applied to insert selected data items and add specific advice (completion step). The interpretation rules for hepatitis A and B serology are structured such that all possible combinations of findings can be interpreted and there is no overlap in the premises underlying these rules. Thus, the rules occasionally group a very high number of combinations of findings into one category of interpretation. An example of an interpretation rule for hepatitis B serology is given in Figure 1.

Rule II-101:

**IF**

\[
\begin{align*}
| \text{HBsAg} & | \text{anti-HBsSUM} & | \text{anti-HBc} & | \text{Igm anti-HBc} & | \text{HBeAg} \\
| \text{anti-HBe} & | \\
| -/+ & | + & | * & | I1 & | I2 & | +/- & | * & | - \\
| -/+ & | - & | +/- & | * & | - \\
\end{align*}
\]

**THEN**

This constellation of findings (positive anti-HBs antibodies, with negative IgM anti-HBc antibodies) indicates the presence of immunity to the hepatitis virus B. This immunity may either have been acquired naturally upon restitution following a hepatitis B virus infection or may have been induced by active or passive immunization. Vaccination recommendation: If an indication for a hepatitis B vaccination exists, the primary course of immunization has been completed, and the last partial vaccination was given at least 1 month previously, an immediate hepatitis B booster shot is recommended to maintain the immunity. If the person is suspected of being a 'low responder' a titre check 2 months after the booster is advisable.

Figure 1: An example of a rule for hepatitis B serology interpretation. The premise of the rule should be read as follows: + = 'positive', - = 'negative', +/- = 'borderline', and * = 'not tested'. A fictitious test, called anti-HBsSUM, is introduced. This test can not only assume +, -, +/-, and * but also the values I1='in interval [1,10]', I2='in interval [11,34]', I3='in interval [35,79]', and I4='in interval [80,...]'. Several entries in one table element are connected by an 'or'; several table elements in one row are connected by an 'and'; and several table rows are connected by an 'or'.

In analyzing serologic test results, the HEPAXPERT-III program compares the constellation of serologic findings with constellations that may occur in the course of hepatitis A or B infection. Possible active or passive immunization is taken into account as well. However, there are several possible sources of misinterpretation, such as deviations in the course of the disease from the assumed courses, as well as falsely positive and falsely negative findings. Therefore, in each case the program's conclusions have to be correlated with the patient's overall clinical picture.

HEPAXPERT/WWW can be reached by URL _http://www.med-expert.co.at/hepax_ of the World Wide Web. After selecting HEPAXPERT/WWW, serologic test results can be entered and will be transferred as an e-mail message for subsequent interpretation which is done off-line with HEPAXPERT-III. The textual interpretation is sent back via e-mail.
3. Results

The reports that the system automatically generates include (a) the transferred results of the tests, (b) a detailed analysis of the results, including virus exposure, immunity, stage of illness, prognosis, infectiousness, and vaccination recommendation, and (c) optional: an ID to distinguish the origin of the interpretation requests. In clinical use the physician providing the specimen for testing is free to request individual findings; in addition, the laboratory is permitted to issue findings that are not unambiguously positive or negative, so that it will be possible to interpret incomplete and uncertain results as well as prototypical results. Furthermore, as a check on the laboratory results, any inconsistent combinations of findings are identified. It is thus possible to review the findings before they are transmitted to the ward. The HEPAXPERT-I and -II programs has been in routine use at the hepatitis laboratory of the University of Vienna Medical School since September 1989. The structure of the knowledge base has resulted in an exceptionally practice-oriented and efficient interpretation program, among whose merits are convenient data input and interpretation of findings in a matter of seconds. Its acceptance among physicians is high. HEPAXPERT/WWW is available since August 1995 and there are up to 10 requests per week. In August 1996 the interpretation process of HEPAXPERT/WWW was changed from HEPAXPERT-I to HEPAXPERT-III to enhance the system with the quantitative anti-HBs titre test result which is then used to make vaccination recommendations.

4. Requirements

HEPAXPERT/WWW can be accessed from (presumable) any WWW-browser and through (presumable) any e-mail-system.

5. References


