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Models of Telehealth

An Invitational Workshop

February 27-28, 2004, McGill University, Montreal, QC

Co-hosted by
CANARIE and Canada Health Infoway



A report prepared by
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Models of Telehealth – An Invitational Workshop Report

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Models of Telehealth - An Invitational Workshop

Co-hosted by CANARIE Inc. and Canada Health Infoway
McGill International Executive Institute, Faculty of Management, McGill University
Montreal, Quebec, February 27-28, 2004

Words from the Hosts

CANARIE

In Canada, our healthcare system is built on the values of Canadian society. We demand universal access to healthcare for our children, our parents and ourselves. Delivering on that promise depends on developing advanced skills and new ways of delivering health services to Canadians so everyone has the opportunity to access and benefit from advancements in health science. The way we think about health and healthcare is changing. CANARIE's e-Health Program fosters collaboration among educators, scientists, private businesses, and all levels of government so that Canada can harness the power of technology to deliver health services to Canadians regardless of where they live and work. From developing systems that help members of the deaf community communicate with their physicians, to delivering remote diagnostic capabilities to rural communities, projects funded in CANARIE's e-Health Program are changing the way healthcare is delivered in Canada, making life better for Canadians.

As CANARIE's e-Health Program concludes its Phase 3 activities, CANARIE is pleased to have had the opportunity to work with Canada Health Infoway to showcase the CANARIE Phase 3 e-Health Projects at the 'Models of Telehealth' Workshop. In addition to promoting research and development required to build the next generation networks, CANARIE has played the role of catalyst and a facilitator of collaboration, by bringing together expertise and players from a number of sectors to stimulate and foster the creation of innovative applications and services in health and education, seizing opportunities and maximizing capabilities provided by advanced network infrastructures.

The purpose of the workshop was to learn what has been accomplished, what benefits have been realized, and what lessons, advice and knowledge should be shared with the next generation of Telehealth users and developers. This report is a summary of the Workshop, and CANARIE is proud to have been involved.



Andrew K. Bjerring
Président et chef de la direction
CANARIE



Dr. Mo Watanabe
Director, E-health Program
CANARIE

Words from the Hosts (Cont'd)

Canada Health Infoway (*Infoway*)

Canadians view the health system as a cornerstone of their national identity. *Infoway's* mission is to foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis, with tangible benefits to Canadians. *Infoway* will build on existing initiatives and pursue collaborative relationships in pursuit of our mission. Understanding telehealth influencers, stakeholder and user groups, is a fundamental part of *Infoway's* Business Plan.

It was with great pleasure that *Infoway* could contribute to the invitational "Models of Telehealth" Workshop that showcased CANARIE's Phase 3 e-Health Projects. The resulting transfer of knowledge and lessons learned are valuable to the future of Telehealth in Canada. *Infoway* is proud to be part of such a promising and enthusiastic Telehealth Community. Special thanks to all volunteers, sponsors and participants.



Nancy Desormeau
Vice-President, Communication, Information, Adoption
Canada Health Infoway

Main Messages

Based upon the presentations given by Workshop participants, the overall accomplishments, benefits, and lessons learned from the Phase 3 e-Health Program and SIP projects are summarised below.

I. Accomplishments

The main accomplishments are grouped into five categories.

- a. Telehealth prototypes were developed, tested, and validated.** These prototypes included applications specific to: a) special needs e.g. hearing impaired; mental health; First Nations, b) special environments e.g. marine, rural remote, inter-jurisdictional, and c) special care services e.g. home telehealth for wound care, and care of chronic illnesses (diabetes, cardiac).
- b. Hardware and software products that could be commercialized were developed.** Examples included: i) hardware e.g. mobile patient unit to facilitate sitting or laying; mobile homecare kit with peripheral devices; wireless PDAs for diabetes management, and ii) software e.g. case management software; electronic referral software; privacy and security software; software for research investigation, interpretation, analysis, and computational tools; and optimizing prescription management.
- c. Web-based virtual community networks were established.** Examples of these were: i) a cardiovascular health community of nursing practice and public information, ii) a dementia network support group for family care-givers, and iii) an inter-organizational client information exchange network within a non-integrated information system environment.
- d. Telehealth Frameworks were developed.** For example: i) A framework of telehealth readiness for rural and remote communities was constructed. Within this, precise definitions and readiness tools that allow communities to determine their own readiness level for telehealth were developed; ii) a framework around outcome indicators that provides specific definitions and indicators in four areas - 1) quality, 2) access, 3) acceptability, and 4) cost; iii) a proof-of-concept telehealth framework that could be implemented to demonstrate an integrated e-health system; and iv) an EU-Canadian framework that could be used for future EU-Canada partnership collaborations.
- e. Knowledge Management tools and architecture to support:** i) the practice of evidence-based medicine specific to research in areas such as cardiovascular, pulmonary, and oncology as well as drug therapy, ii) data, diagnostic imagery integration, analysis and computation tools, and iii) storage grids.

II. Benefits

Collectively the results of the funded projects presented trends and initial evidence that showed benefits could occur to eight stakeholder groups:

- a. The public** e.g. self-management and empowerment tools; care-giver support tools
- b. The patient** e.g. reduced travel, shortened wait times, increased patient safety; increased confidence in disease management
- c. The health practitioner community** e.g. decreased staff hours; rapid access to health information components to make more informed timely decisions; improved professional networking; team collaboration; new hardware and software tools.

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- d. The health care system** e.g. More efficient referrals, reduced duplication of tests and diagnostic procedures, efficiency of patient services delivery; new readiness, networking, management and policy software tools; indicators of needed future policy foci;
 - e. The private sector** e.g. market intelligence; commercialized products; partnerships and networking; and standard development requirements.
 - f. Geographical locations** (rural remote communities) e.g. New professional and care networks; less travel.
 - g. Special groups** (Hearing Impaired, First Nations) e.g. Linkages to caregivers; case management software; increased staff communication.
 - h. Research community** e.g. standardized definitions, indicators and measures; funding and partnership opportunities; shared best practices; signals for future research; awareness of emerging grid and computational software to manage large networked data and imagery requirements.

Strong evidence for long term sustained beneficial outcomes or end points are difficult to estimate from the health perspective, as the mainstreaming of clinical telehealth services has just recently been implemented. Further, benefits to industry are limited due to the current state of commercialization and market potential for telehealth tools.

III. Lesson Learned and Actions to Move Forward

There were four categories of lessons learned (characteristics of applications, operational, research/evaluation, funding) and nine recommended focus areas (knowledge management, integration, policy, alignment, social marketing, change management, industry partnerships and collaboration, funding, and research/evaluation) identified by workshop participants. Taking these into consideration will enable the telehealth community to move its agenda forward. Specifics are detailed in the Workshop's Group Discussion final session (pg 51).

Executive Summary

Through its Phase 3 e-health program, CANARIE has funded projects intended to move Canada's investment in e-health forward, harnessing the power of information and communications technology to the benefit of all, regardless of location. Technology solutions have included growing network development, IP based applications, use of increasing broadband capability, and examination of third wave technology options. Behind the technology, projects have also examined fundamental issues such as privacy, readiness, outcomes, cost, and utility. The purpose of the Workshop, co-hosted by CANARIE and Canada Health Infoway, was to bring the project groups together and to learn directly from them what has been accomplished, what benefits have been realized, and what lessons, advice and knowledge could be shared with the next generation of Telehealth users and developers.

Section I focuses on reports from Phase 3 e-Health Program projects, Section II focuses on projects funded through the Strategic Initiative Program, and Section III outlines three special presentations, the first from Canada Health Infoway on the *Infoway Telehealth Strategy*, the second from McGill University on drug prescription management, and the third by National Research Council (NRC) on the electronic patient record. Appendices provide supporting information related to the workshop. Each project description is concluded by commentary summarising what has been accomplished, what benefits have been realised, what lessons learned, advice, or knowledge can be shared, and the project partners. The overall accomplishments, benefits, and lessons learned have been summarised in the 'Main Messages' section of this report.

Section I Program Projects were categorised according to their primary focus. 'Special Groups and Special Environmental Needs' section describes three telehealth projects addressing the distinct needs of special groups or environments. One examined the application of telehealth to provide interpretive services to hearing impaired people seeking healthcare support; another tested the use of telehealth in the marine environment on board ship; and the third considered the inter-jurisdictional and international environment in the community of Akwesasne that straddles several borders.

The 'Outreach' section describes projects that utilise videoconferencing in support of patients with chronic diseases. These examined support into the home, development of a virtual community of practice, and the wireless monitoring of patients.

The Section 'Empowering through the Internet' looked at Internet-based applications that empowered one or more groups requiring healthcare or health information. The first provided information and interactive support to caregivers of dementia patients, the second created a Web Of Wisdom that enhanced patient care and care-team wisdom, the third enabled an established chronic care model using PDA's to support chronic care management in diabetes.

The section 'Innovative Product Development' describes projects that developed distinctive innovative products. The first described a PC based tool, being migrated to a mobile format, which provides evidence-based information at the fingertips. The second presented a software product (Doc2Doc) that supported electronic patient referral between family physicians and specialists. The third detailed a product that approached privacy and

confidentiality through providing a unique means of protecting sensitive material, even after having been distributed. This means was termed “persistent security”.

The ‘Beginning to End’ section brought together projects that had been designed to provide support to the broader telehealth community through examining issues of import to most, if not all, telehealth projects from their initiation to completion. The first investigated and developed tools to allow various communities to assess their readiness for engagement in pursuing telehealth solutions. The second, through survey evidence, described the value of supporting the preparation and dissemination of reports of conferences and workshops. The third investigated and described the area of outcomes measurement in telehealth, and defined and developed a core set of telehealth outcome indicators.

Projects within the ‘Third Generation Technology’ section described initiatives exploring third wave technology applications. The first project developed an integrated information model that captures, mines, and analyses vast quantities of clinical and research data. The second explored the application of grid computing in the transmission and storage of diagnostic imagery. The third described a secure, electronic internet-based information exchange mechanism designed to address the current fragmented and dispersed nature of client information currently held in different parts of the healthcare continuum. The final presentation in Section 1 described development of a prototype web-based tool to handle, in an object-oriented manner, information from different sources and contexts in the oncology and cardiac arenas.

Section II described two projects funded under the SIP. The first described an important landmark in the history of telehealth in Canada, and used the opportunity to explore the transition of telemedicine to e-health, and to plot options for future e-health development. The second described a successful program designed to promote EU-Canada collaboration in health telematics systems and services.

The special presentations (Section III) by Canada Health Infoway, McGill University, and the National Research Council (NRC) described the new Telehealth mandate, a drug prescription management project, and a new Personal Health Record initiative of each group, respectively. *Infoway* noted that most grant opportunities in the past supported technology or provider and clinical services infrastructure, with little attention given towards governance and management infrastructure. As a result, true integration of Telehealth into mainstream healthcare has not occurred, with Telehealth in Canada remaining fragmented and less than optimally used and adopted. *Infoway’s* Telehealth program is intended to specifically address these issues, and is intended to make a first phase of investments in 4 key areas: Technical standards, scheduling system requirements definition, enablers and investment stimulus. McGill University is leading the application of an e-health initiative in the area of pharmacotherapy. Termed the Medical Office of the 21st Century (MOXII), the program optimizes drug prescribing and use. Benefits and value-add are significant, and include alerts for drug-drug and drug-disease interactions at the time of prescribing, awareness of all prescribed medications for a patient, identifying and resolving compliance issues, providing automated refill reminders, identifying problem prescriptions, enhancing team management through e-referrals and shared care models, and use of CPG’s to facilitate evidence-based decision support. Further work will move this from a PC-based model to a mobile (PDA) based model. NRC stated that, through its newly created Institute for Information Technology (IIT) initiative, it will focus research and development efforts to create a national Personal Health Record (PHR) capability. The basic structure and content will be available to all Canadians on a voluntary basis, and will have both generic health

related information as well as personal health information of the individuals choosing within their own secure record.

From the information provided by each Workshop participant, it was possible to summarise accomplishments, benefits, and lessons learned, as well as to provide recommendations for moving telehealth forward. This constitutes the cumulative wisdom gained through CANARIE's Phase 3 e-Health and SIP projects. Main accomplishments included: the development, testing, and validation of telehealth prototypes; development of hardware and software products capable of commercialisation; establishment of web-based virtual community networks; development of telehealth frameworks; and development of knowledge management tools and related architecture. Benefits were also identified that related to 8 stakeholder groups, and ranged from self-management and empowerment tools for the public, through to standardised approaches, shared best practices, and enhanced awareness for the telehealth research community. Further lessons learned were categorised into four groups around characterization of applications, operational issues, research and evaluation issues, and funding issues. Finally, additional perspectives to support moving telehealth forward in Canada were gleaned during a Group Discussion that identified nine focus areas: knowledge management; e-integration; policy; system and IT alignment; social marketing; change management; industry partnerships and collaboration; funding; and research and evaluation.

Introduction

The Models of Telehealth, an Invitational Workshop, Co-hosted by CANARIE (Canada's Advanced Internet Organization) and *Infoway* (Accelerating the Development of Electronic Health Information Systems for Canadians), was held February 27-28, 2004 in Montreal, Quebec (Program Appendix 1). The Workshop was made possible through contributions from CANARIE Inc., *Infoway*, Health Canada, McGill University, MedTech Partners Inc., Evidence Matters, and the National Research Council. Approximately fifty people attended the Workshop – 21 presenters and ~29 attendees (Attendee List Appendix 2). Session Moderators included: Mo Watanabe, Pierre Levasseur, Penny Jennett, Erin Keough, Wayne Boyce, and Rafiq Khan. A wine and cheese reception at the McGill Faculty Club at the conclusion of the first day, provided opportunities to continue discussions, identify potential future collaborations, and to develop new networks and linkages.

The Models of Telehealth Workshop showcased Phase 3 activities of CANARIE's e-Health Program and two Strategic Initiative Projects. Its purpose was "to learn what has been accomplished, what benefits have been realized, and what lessons, advice and knowledge could be shared with the next generation of telehealth users and developers." Further, the Workshop informed *Infoway* in examining the "best strategies for adoption of various facets of a new business management model for the service delivery channel known as Telehealth, and the specific elements that would support the model, such as standards, management, and partnership."

Welcome Remarks

Dr. Andrew Bjerring – President and CEO, CANARIE

Dr. Andrew Bjerring, President and CEO, CANARIE, welcomed the participants, noting that this Workshop was a celebration of the completion of the CANARIE projects and the current e-Health Program, as well as a celebration of a decade long achievement in the area of telehealth/e-health.

CANARIE began discussions with *Infoway* two years ago to understand *Infoway*'s objectives, and identify potential collaborative opportunities. This led to this Workshop co-hosted by CANARIE and *Infoway*.

This Workshop provides the opportunity for the CANARIE funded projects to tell their stories, as well as to showcase successes, benefits, and lessons learned with the next generation of telehealth users and developers.

Dr. Bjerring thanked the Workshop sponsors – Health Canada, Med Tech Partners Inc., McGill University; the National Research Council, and Evidence Matters, without whom it would be very difficult to hold this event. He also thanked those who had contributed to CANARIE's e-health activities. CANARIE's role is to facilitate and help the community to achieve its objectives, one vehicle being the e-health projects being showcased at this Workshop.

Dr. Bjerring recognized the significant effort of Dr. Watanabe, noting his involvement ten years ago with the Information Highway Advisory Committee representing telehealth. At the same time, CANARIE was initiating a vision for telehealth, and discussions developed. With Dr. Jennett's help, a CANARIE vision statement for telehealth was developed. Dr.

Watanabe has now been with CANARIE for 10 years, and continued to lead e-health activities. Dr. Bjerring publicly thanked Dr. Watanabe, on behalf of CANARIE.

Dr. Abraham Fuks, Dean, Faculty of Medicine, McGill University

Dr. Fuks welcomed the participants on behalf of the Faculty of Management and Faculty of Medicine, indicating that this Workshop represented a series of projects important to the Faculty and the University. One of the McGill Projects being showcased at the Workshop is one of a series of interface projects between the Faculty of Management and the Faculty of Medicine at McGill University. Dr. Fuks thanked CANARIE for their funding assistance in this Project, as well as other McGill Projects. The Workshop Program was impressive, with its diverse audience, the variety of disciplines represented, and the emphasis on the messages to be received as opposed to the methodologies. The Program looks at what the families, communities and patients require, as opposed to what is convenient for the caregivers. Further, the Program focuses on communities, not just individuals, and looks at what the person needs to return to their work, school, family and home environment. Telemedicine facilitates important people-to-people communication and clinical skills. There is a need for evidence, by way of outcome measures, that quality care is going to be as good with telemedicine as with traditional care. The Internet has become a wealth of knowledge, well-liked by all. That is sometimes overwhelming as we forget the difference between what we want to know and need to know to achieve a specific clinical objective. Dr. Fuks congratulated the organizers putting together such a balanced Program.

Nancy Desormeau – Vice-President, Communications, Information & Adoption; Program Director, Telehealth, Canada Health Infoway

Nancy Desormeau welcomed the participants. This is the first telehealth event for *Infoway* since the Phase 1 Telehealth Investment Strategy was approved in the end of January. Many of the participants at this Workshop have been supporting telehealth and been leaders of telehealth for a number of years. This Workshop provides an opportunity to bring the people together, so that *Infoway* can share their analysis of telehealth and outline the structure for their telehealth portfolio. Through the *Infoway* Telehealth program, the hope is to make telehealth sustainable, alleviating the need for competitive funding competitions. *Infoway's* analysis is that it's not just about the technology, but about the "merger of the management of the technology and the management of telehealth", and learning new ways to communicate. This has played a role in deciding how the *Infoway* Telehealth Program has been structured. (See Section E – Infoway's Telehealth Investment Strategy)

Section I: e-Health Initiatives

A. SPECIAL GROUPS AND SPECIAL ENVIRONMENTAL NEEDS

Telehealth and e-health applications bring promise of better access and better health to Special Groups, as well as Special Environments.

1.0 MIST: Marine Interactive Satellite Technologies Carl Robbins, TETRA, Memorial University of Newfoundland (E. Keough presented). St. John's NF

The Marine Interactive Satellite Technologies (MIST) wireless sickbay project implemented a technology model for the delivery of telehealth services into mobile marine environments. The test site was Atlantic Canada. This specific marine environment has the world's busiest fishing and shipping areas, growing offshore oil and gas, Coast Guard and increasing cruise industry. The telemedicine solution was fitted to the Joseph and Clara Smallwood, a super ferry, which provides trips between the ports of Argentia NL and North Sydney NS (13 hours at sea each way). The goal of the project was to provide distance responses by physicians located at the Charles LeGrow Health Centre in Port Aux Basques, Newfoundland to address medical problems on the ferry. Telehealth services were provided by satellite connectivity and ground base wireless platform.

The implementation of the Wireless Sickbay project involved: design of requirements, acquisition of equipment, installation of the hardware and software test network, and training sessions of personnel, both on the vessel and at the LeGrow Health Centre. MIST used two teleconsultation technology models: 1) simple voice communications, which linked a crewmember to a physician on-shore; and 2) real-time video and patient vital signs teleconsultation, using the RCST/IEMN standard, between the health facility and the vessel. The evaluation methodology included log data; satisfaction questionnaires for: Patient/Client, Health Professional; and Key informant (telehealth committee) input. The evaluation objectives were to provide data on the telehealth technology, the MIST consults types, and the satisfaction of the patient and health professional using the technology. During the field trial period (August to September 2002), 41 sessions were attempted/conducted with three types of consults: "1) Point to Point Check-in / simulated consultation with an on board personnel (Chief Steward); 2) Point to Point Emergency Volunteer Patient consultation; and 3) Urgent/Emergent health situations" consultations. Type 1 and 2 consults were field tests and Type 3 consults were "live". Of the 37 tests, 46.34% of calls were unsuccessful in connecting. The four "live" consultations addressed abdominal pain, neck injury, dressing change, and motion sickness.

What has been accomplished?

- A telehealth prototype for mobile marine environments was developed and validated.
- An evaluation framework and process were developed, which determined the viability of the concept.

What benefits have been realized?

- A medical remuneration solution for this telehealth application was developed.

- This application may extend beyond Canada's Atlantic marine environment to the Pacific west coast, Arctic regions, Canadian Coast Guard and the Canadian Navy whose off-shore missions are of long duration.

Lessons Learned/Advice/Knowledge for Sharing:

- Knowledge of environmental context is critical
- Emphasis on training of personnel is essential
- User controlled "bandwidth-on-demand" technology is needed
- There is a need for standardized protocols and guidelines
- There is ongoing need for communication and better project management
- The project had inadequate time to understand and reconcile the differing cultures among ship's crew, physicians on call and the research team.
- The application could use nurses instead of physicians in port of calls.
- There is a need for technical quality and support
- In rural/remote environments (e.g. Off shore), combination projects (more than health application) are required for sustainability
- For specific applications, special technologies are required, e.g. Gyroscope.

Project Partners:

Telesat Canada, TETRA, Colabnet, The Communications and Research Centre (CRC), the Marine and Mountain Economic Development Corporation, Marine Atlantic, Canadian Centre for Marine Communications (CCMC), and the Canadian Network for Research, Industry and Education (CANARIE). CANARIE contributed \$110,000 for the telehealth application. The two components, in addition to the Telehealth, were 1) Teletourism (Kiosks); and 2) Business Applications (Internet access).

2.0 Native Mental Telehealth

Ann Seymour, Melinda Villeneuve, Akwesasne Mohawk Council. Akwesasne ON

The community of Akwesasne is governed by the Mohawk Council of Akwesasne. It overlaps the Canadian and U.S.A. border, and has a population of 13,000; approximately 9,000 live in Canada. Further, Akwesasne straddles the Ontario and Quebec border, and lies adjacent to the St. Lawrence River. This Canadian community is divided into three districts: 1) St. Regis 2) TsiSnaihne Quebec, and 3) Cornwall Island.

Akwesasne faces addictions, personality and developmental disorders that are rising among its youth. Clients typically travel 1 ½ to 2-hour drive to Ottawa for care. This is at times, expensive and stressful. A telehealth solution was approved in 2003.

Three complete units were installed at three different sites: 1) St. Regis Health Facility, 2) Group Home on Cornwall Island, and 3) Satellite Office at the Royal Ottawa Hospital. Each complete unit was composed of a "Polycom VSX 7000, or Group Home or Polycom FX (SR & ROH), VPN service unit, video conference phone (as an alternative back up), and a video camera recorder. The project uses 2 types of ISDN: wireless and fibre optics. Calls initiated at the Group Home use fibre optics. The St. Regis health facility uses 384 mb dial up and 6 ISDN PRI connections. The Royal Ottawa Hospital uses 384 mb and 3 ISDN BRI connections. A server room houses the ISDN connections. The Atlas 500 equipment facilitates moving the videoconference equipment anywhere within the building. Eight months were required to establish connectivity. The staff includes: six technicians, a data

base developer, and a software trainer. Currently there are on going consults between the client and doctor from both the Children's Hospital of Eastern Ontario (CHEO) and the Royal Ottawa Hospital (ROH). The first "live" client session occurred in January 2004. There were seven sessions in this month. To-date, in February, there has been five. The focus has been on mental health. The key factor that has determined the number of sessions is physician availability and number of client intakes. The evaluation of the project has been rated highly and exceeded expectations.

What has been accomplished?

- Designed and implemented a viable Native Mental Telehealth application that crosses jurisdictions and borders.
- The development and deployment of Case Management Software.

What benefits have been realized?

- The major benefits have been decreased travel; staff hours, timeliness and savings in costs.
- The opportunity to access specialized mental health professionals.
- The strengthening of partnerships from increased client sessions and communication with other health professionals.
- An increase in the dialogue among staff.

Lessons Learned/Advice/Knowledge for Sharing:

- Staff training increases awareness of telehealth technology resulting in increased usage.
- Additional funding is required
- Telehealth may be utilized in other areas besides mental health, for example: cardiology, diabetic clinics, dental, child and family services, physician to worker consultations, education sessions, and clinician-to-clinician consults.
- Connectivity was very challenging involving the use of fibre optics, wireless, ISDN and IP.
- Akwesasne community will extend telehealth to support clinic and nursing homes.
- The project could be applied to other Haundenosaunee communities.

Project Partners:

CANARIE, the Mohawk Council of Akwesasne, Royal Ottawa Hospital, Children's Hospital of Eastern Ontario, and ARC.

3.0 Deaf Communities Using Internet Video Technology to Improve Health Care Delivery To People Who Are Deaf Glen Hughes, University of New Brunswick. Fredericton NB

The Eldridge decision by The Supreme Court of Canada "ruled that the failure to provide sign language interpretation in the delivery of health care services where it is necessary for effective communication violates the Charter of Rights of Deaf Canadians". This project evaluated the use of "internet based video communication equipment as a potential solution for providing remote interpretation services to people who are Deaf in a medical setting". People who are Deaf, health professionals and sign language interpreters were involved in "mock" health care conditions that simulated real life settings at hospital emergency rooms, medical clinics and health care professional offices. These simulations "occurred in five

locations within New Brunswick (NB), Moncton, Saint John, Bathurst and Fredericton with the remote interpreters located in Fredericton, Saint John or Montreal, Quebec”.

South East Deaf and Hard of Hearing Services (SEDHHS) and Saint Johns Deaf and Hard of Hearing Services (SJDHHS) provide interpreters for approximately 1,000 people in New Brunswick. The two sign languages used are ASL (90% of the population) and LSQ (10% of the population). Only 5 ASL interpreters are qualified to interpret in medical situations, and no LSQ medical interpreters – a LSQ interpreter must be flown in from Quebec.

A mobile unit was developed which allowed the patient to be in a sitting position or lying on an examination table. The technical equipment used two models: 1. Polycom SP128 stand alone unit with 27” TV monitor, and 2. Polycom ViaVideo camera with a desktop computer and 17” flat panel display mounted on an infusion pump stand. The client unit was the bigger challenge: the equipment needed to be adjustable, mobile, accessible when sitting or laying down, and cost effective (i.e. low cost alternative). Connectivity used ADSL Internet, 1.5 Mbps download, 640 kbps upload, and the project systems set at 384 kbps.

There were 40 simulated sessions. At the end of each simulation, participants (24 clients, 4 interpreters, and 14 information providers) completed questionnaires covering three aspects: 1) the session characteristics (e.g. the health condition being simulated; time and length of session; number of times the equipment moved; and the time spent moving the equipment and why it was moved); 2) the technology quality (e.g. Was the picture clear?); and 3) the session experience (e.g. Did you have to repeat more often than when the interpreter is in the room with you?) An informed consent process in sign language, as well as English and French was developed. Session topics included: “sore throat, arthritis, chest pain, gall bladder, whiplash, knee injury, stress, depression, informed consent, food poisoning, social assistance...” The analysis and feedback from the questionnaires was very positive.

What has been accomplished?

- The implementation of a telehealth solution “as a way of accessing sign language interpretation services from a remote location by people who are Deaf when accessing health care services”.
- The development of a mobile unit that facilitates “people who are Deaf to communicate with an interpreter in either a sitting position or while lying on an examination table”.
- The development of an appropriate informed consent process in sign language, as well as in English and French.
- The delivery of LSQ interpretation services to a client outside the province of Quebec.

What benefits have been realized?

- The increased access to LSQ and ASL medical interpreters and reduced travel.
- The testing of the equipment resulted in clarity of communication, speed of movement, and ease of use.

Lessons Learned/Advice/Knowledge for Sharing:

- Implementation of the telehealth solution requires access to technical support and orientation/training.
- Health providers need to remember to look at the patients and not the screen.

- Interpreters were concerned about the appropriateness of the project for legal, mental health and job-training situations where they felt a physical interpreter should be present. Further, interpreters were concerned about technological problems, and the effect on rapport, respect and trust.
- Some individual health professional would prefer to see the interpreter; however not having the interpreter present in the room was less distracting.
- A public awareness campaign should precede implementation.
- There is a need for standardized policies and procedures.

Project Partners:

CANARIE, South East Deaf and Hard of Hearing Services, Saint John Deaf and Hard of Hearing Services, Canadian Deafness Research and Training Institute, New Brunswick Easter Seal March of Dimes, Association of Visual Language Interpreters of New Brunswick, New Brunswick Innovation Foundation, and the University of New Brunswick.

B. OUTREACH

Although telehealth can be tailored to unique societal and environmental needs, it also can be harnessed to enhance community based care, professional communication, and the management of chronic diseases.

1.0 East York Telehomecare Project Dr. Diane Duff and Dr. Lynda Atack, Centennial College. Scarborough ON

The East York Telehomecare (THC) project is a video-based telehomecare application for patients living with chronic illnesses. The initial focus has been on chronic obstructive pulmonary disease, diabetes, and congestive heart failure. The diverse team of health care providers (Community Care Access Centre case managers, community nurses, family practice physicians, and the Toronto East General Hospital clinical nurse specialist for ambulatory care, the diabetic educator, and the clinic nurses and physicians), educators, and researchers' project goals were to:

- Implement the video-based THC for patients with chronic illness who use an integrated health system to improve health outcomes.
- Research the experiences of both patients and providers using THC.
- Evaluate the access and costs associated with THC delivery.
- Document the implementation of THC - the process, models and guidelines.

The technology includes: 1) a work station with a camera on top at the clinic; 2) a patient station at the home the size of a breadbox, with peripheral devices such as headphones, a stethoscope, blood pressure reading devices, and weigh scales; 3) two stations with the community care providers; and 4) one at East York for the case managers. "The technology has been reliable and the technology provider has been exemplary in the provision of support and training".

Of the 27 patients referred for THC, 24 participated in the project. Problems associated by the non-participants were: no telephone, re-admission to hospital prior to intake, in-home visits deemed more appropriate, client undergoing stressful situation(s), and dislike of the THC technology. Two hundred and forty-nine (82%) remote THC visits and 55 (18%) in-home visits have occurred to date. The majority of the in-home visits were: 1) to install and learn to use the THC equipment; and 2) to remove the THC equipment on discharge.

Patient ages ranged from 60 – 93 years. Sixty-eight percent were male clients. The length of stay on THC ranged from less than 1 week to 22 weeks. THC visits ranged from 1-147, with an average of 14 visits. No patients involved in the THC project had ER encounters or in-patient hospital stays while using telehomecare services, and “no patients were discharged due to a hospital admission”. Interviews with patients and providers indicated an overall satisfactory/good experience. The interviews to date have identified the following unaddressed issues: “organizational readiness; referrals and recruitment; funding/reimbursement; clinical practice, support, and training; health outcomes/patient satisfaction; cost savings/prove it to support return on investment; and sustainability of the THC project”. Patient admission has been slow due to homecare funding restrictions associated with SARS and pre-existing relationships between non-telehomecare health providers and their patients. Ongoing and further evaluation using such approaches as “grounded theory” will be used.

What has been accomplished?

- The design and implementation of a video-based telehomecare services for patients with chronic illnesses accessing an integrated health care system.
- The documentation of the THC implementation process, models, guidelines and experiences of the patients and providers.
- Evaluation of the THC technology and technology users (providers and patients).

What benefits have been realized?

- THC has increased remote access to a diverse team of health care providers for patients.
- The validation of the reliability of the THC technology, and technology provider.
- Patients using THC live more confidently with their illness.

Lessons Learned/Advice/Knowledge for Sharing:

- Establish clear project goals/ responsibilities for all partners and ensure commitment.
- Recognize a need for regular on-going communication.
- Note the need for involvement and commitment of key people at the onset, especially the clinicians.
- Prepare the workplace: the environment, IT, and work processes (organizational readiness, including clinical practice, support and training).
- Demonstrate equipment early in the project.
- Network with a wide referral base, and include research organizations.
- Arrange for “dedicated salaried positions to the project in each organization i.e. THC nurse, THC portfolios for managers, secure a project manager”.
- Preserve current relationships; referrals and recruitment.
- Watching health outcomes/patient satisfaction is key
- Need to prove the sustainability, cost savings and return on investment

Project Partners:

CANARIE, Centennial College, East York Access Centre, Comcare Health Services, Toronto East General Hospital and Family Physicians, American TeleCare Inc., and the Ontario Innovation Trust.

2.0 Remote Access Virtual Nurse

Marie-Josée Paquet, Ordre des infirmières et infirmiers du Québec. Montreal QC

In March 2002, the Ordre des infirmières et infirmiers du Québec (OIIQ) established a cardiovascular health virtual community of practice (Virtual CoP) to test a new method of professional cooperation using the Internet. There were 33 cardiovascular nurses from Quebec (30), Ontario (2) and New Brunswick (1) involved in the project. The goal of Virtual CoP was to investigate its development, processes/functioning, evolution and outcomes. Virtual CoP was a component of a larger research project, initiated by the Centre francophone l'informatisation des organisations entitled "Work and Collaboration Methods in the Internet Age". A virtual CoP is a group of people who share a common interest in a field of practice where they exchange information, views, advice to solve problems, advance knowledge, produce common deliverables and capitalize on Internet technology.

Nurses shared, built and managed knowledge regarding their area of expertise to resolve issues arising in the field. They were also asked to develop nursing knowledge suitable for the public focusing on prevention and self-empowerment in cardiovascular health, which could be published on the L'infirmière virtuelle web site (www.infirmiere.net). There are over 30, 000 visitors to this website each month. Virtual discussions occurred from March 18 to September 30, 2002. Application software for Virtual CoP was Knowledge Forum (KF) which facilitates cooperative networking, development of virtual exchange rooms, writing exchange notes (data fields for problems, helpful data, questions, solutions and views) and cognitive building, and uses neuronal architecture. The virtual exchange rooms:

- Knowing each other better (1 room) – participant introductions and digital photo.
- Sharing knowledge (4 rooms): Room 1 - innovations in cardiology; Room 2 - cardiovascular health brainstorming and related topics; Room 3 - professional tools; and Room 4 – virtual library.
- Solving problems (2 rooms): Room 1 – current, ancient or recurring problems; Room 2 – practice related queries.
- Producing deliverables (1 room) – cardiovascular health kit for discharged hospital cardiac patients and general public, which covered topics of health risks, heart failure, angina and infarction, and planning a trip.

Each participant received formal training on KF. The Virtual CoP project showed that the Internet is a complementary tool that can facilitate communication and cooperation among professional nurses who are unable to meet regularly in person. "Virtual communities of practice can also share and build a knowledge base and act as a group learning forum". At the conclusion of the project, 80% of participant nurses expressed continued interest and use of Virtual CoP.

What has been accomplished?

- The design and implementation of a virtual cardiovascular health community of nursing practice in Quebec.
- The shared nursing cardiovascular knowledge has been published on L'infirmière virtuelle web site for access by the general public.
- The project demonstrated an innovative and complementary way to "capitalize and utilize clinical expertise of seasoned nurses; maintain and reinforce nurses' professional abilities at several levels".

What benefits have been realized?

- Increased cooperation amongst participants.

- Sharing of knowledge to resolve issues encountered in practice.
- Increased communication between nurses who might not be able to meet regularly.
- Increased professional support network.
- Update of professional resources.

Lessons Learned/Advice/Knowledge for Sharing:

- Virtual communities of practice can be applied by organizations interested in knowledge management.
- The Internet can be used as a complimentary tool to facilitate communication, cooperation, and learning in professional practice.

Project Partners:

CANARIE, OIIQ, the Canadian Association of Schools of Nursing, the Canadian Council of Cardiovascular Nurses, the New Brunswick Heart Centre, the Laval Hospital, the Ottawa Hospital, the Montreal Heart Institute, Centre francophone d’informatisation des organisations (CEFRIO), Fonds de l’autoroute de l’information (Quebec), and the Information Highway Fund.

3.0 March Networks Telehomecare

Ms. Christine Woronczuk, Assistant Vice-President, Healthcare Applications, March Networks

Dr. Richard Scott, University of Calgary, Health Telematics Unit. Calgary AB (Presenter)

At the time, this represented Canada’s largest home telehealth pilot. The objectives of this 2002 pilot were to evaluate the overall technical feasibility of providing remote video visiting and vital sign monitoring with an IP based telehealth solution utilizing a broadband connection, and to evaluate the impact on quality of care. The project set out to establish the reliability and viability of home telehealth in a live, real-life setting. The randomized-controlled trial with approximately 80 patients was conducted over a six-month period of time, with patients receiving a mix on in-home and remote visits. Vital sign measurements including blood pressure, pulse, SP0₂, temperature and weight, were recorded and charted via a web enabled electronic patient record throughout the trial. An independent evaluation of the pilot was conducted. Study data support the conclusion that home telehealth is effective, provides very high satisfaction to patients and nurses, maintains quality of care, and has the potential for significant cost savings and increased access to care.

Overall results of the pilot were encouraging, and represented a clear value to March Networks in defining the direction for the development of a commercialized telehealth solution.

Characteristic	Homecare	HomeTelehealth
Appointment time	16.4 min	10.5 min
Visit time	24.8 min	10.5 min
Travel time required	19.2 min	None*
Time per patient	44.0 min	10.5 min
Maximum Daily Case Load	8 - 10 Patients	16 - 20 Patients

* ~87 days per annum of nursing time saved through eliminating travel (one way) and 'avoidable delay time' (totals 36% of working year).

Next steps in product development incorporated lessons learned from the pilot from a technical and user perspective, as well as input and feedback received from various healthcare and industry related professionals. Ongoing business activities have focused on the development of partnerships for the deployment of telehealth utilizing 2 way satellite to rural and remote communities, where the value of telehealth can be clearly demonstrated well beyond patient vital sign monitoring and could be considered as an effective tool for the support of remote, and often isolated, health care professionals.

What has been accomplished?

- The outcome has been the development of an end to end telehealth solution that is flexible in terms of deployment options, satisfies a wide range of telemonitoring programs and is designed from the ground up as a complete solution with a long term product roadmap that will adapt as this emerging home based telemonitoring industry grows and matures.
- A partnership model for deployment of services that worked.

What benefits have been realized?

- Nursing time saved by reducing travel time and avoidable delay time.
- The financial support from federal/provincial governments and private sector.
- Formation of partnerships among the public and private sector.
- Increased communication and access for patients living in rural and remote communities to health care services.
- Reduction of travel time and expenses for clients.

Lessons Learned/Advice/Knowledge for Sharing:

- Home telehealth must be economically viable and sustainable.
- The results of the pilot are encouraging in terms of quality, access, acceptance and cost.
- Telehealth looks promising as “a tool for the management and delivery of homecare” on a wide scale/national solution.
- Live demos to policy and decision makers are important ingredients to success.

Project Partners:

CANARIE, March Networks Corporation, WeCare Home Health Services, Aliant Telecom, and University of Calgary.

C. EMPOWERING THROUGH THE INTERNET

The Internet has opened new means of communication for all of us by changing the way we work and the way we gather information of relevance to us. The Internet provides unprecedented access to large quantities of health related information. By providing access to this information, individuals (be they healthy citizens, patients, informal caregivers, or formal healthcare providers) can each be empowered, enabling them to make better decisions. The presentations in this section exemplified different aspects of empowering through the Internet.

1.0 Health Support Interventions for Impaired Elderly and Their Caregivers Elsa Marziali, Baycrest Centre for Geriatric Care and University of Toronto, Toronto ON

This group questioned why only very short-term interventions are given to family caregivers when the patient they must care for is first diagnosed with dementia - a disease known to result in continued and serious deterioration over 2 to 15 years? Use of the Internet as an intervention strategy was determined to be appropriate. The rationale was: long-term support can be made available at minimal cost; traditional face-to-face support mechanisms are economically unsustainable; 24/7 support is required; access to services in rural and remote areas can be enhanced. The literature informed the group about caregiver needs and the cost impact of family care giving. Caregivers costs were ~\$18,385 annually [1998

\$), largely attributed to loss of work, and community care has been shown to be more cost effective to the healthcare system than institutional care. As a result of these studies, the group pursued pilot studies. These studies observed and collected data from 3 face-to-face groups of spousal caregivers supporting dementia patients as they received 10 weekly sessions and were then transitioned to on-line intervention. As a result of these studies the team examined the process of caregiver support, and developed a theoretical framework that encompassed four themes supported by training and education. Four products were developed by the team: an intervention training manual, a computer training manual, disease specific handbooks, and a functional website.

The website uses a simple uncluttered design focused on elderly spouses of dementia patients; this includes intuitive icons, subtle color contrast, well-designed links, and easy access to content. The site incorporates e-mail and question and answer facilities. In contrast to many text-based sites, video chat and videoconference capabilities are supported. Six group members can be on-line simultaneously. The website requires low maintenance and is scalable for future additions.

The website formed the focus for the CANARIE funded field trials in two remote sites (Lethbridge, Alberta and Timmins, Ontario), selected due to the availability of geriatrician champions and high-speed connectivity. A pre-post intervention assessment strategy followed the activities of daily living, behavioural problems, adequacy of resources, and depression of family caregivers of 24 Alzheimer, 24 Parkinson, and 24 stroke patients. Patient and caregiver dyads were recruited through the local hospitals. Participants required a computer, webcam, and headphone set. Only minimal training was required, and preliminary analysis of outcomes is very positive. Ten caregivers (five from each site) were interviewed, and gave overwhelmingly positive responses when asked if it helped them cope, and also indicated they were able to achieve social bonding, cohesiveness, and rapport in this on-line environment.

A functional, effective, secure, and scalable web-based tool has been developed for support of family care-givers of patients with dementia. This solution provides an enhanced caregiver support network that decreases caregiver stress and burden. This solution holds promise for supporting caregivers of other patient groups (brain injury, other chronic mental illnesses, children with chronic conditions such as epilepsy and diabetes). This studies approach may also delay institutionalization of patients. Although difficult to document, even saving one month of institutional care would represent huge cost savings to the healthcare system.

What has been accomplished?

- A functional, effective, secure, and scalable web-based tool has been developed for support of family care-givers of patients with dementia.

What benefits have been realized?

- Caregivers experience reduced stress related to their caring of spouses.

Lessons Learned/Advice/Knowledge for Sharing:

- e-Health facilitated support is welcomed by care givers.
- Website must use simple design and content for and easy access to content.
- The solution may be applicable to other patient groups.
- Costing studies are required.

Project Partners:

CANARIE, Bell Community Development Fund, Bell University Labs, University of Toronto, Eli Lilly & Co., Janssen Ortho Inc., and the Katz Centre for Gerontological Social Work.

**2.0 Evaluating the Transformation of Education and Healthcare Delivery Through a Web of Wisdom (WOW) Approach
Nancy Lefebvre, Saint Elizabeth HealthCare. Markham ON**

The concept of WOW began when reflecting on the burden of chronic diseases on the healthcare system. Recent Federal and Provincial health reports acknowledge that many Canadians, particularly in rural or remote communities, have difficulty in accessing healthcare. New, innovative strategies are needed that deliver healthcare and health support directly into the home. WOW is one such strategy that focuses on providing healthcare and education anytime, anywhere to both patients and providers. It leveraged the collective wisdom of Saint Elizabeth Healthcare teams, and the support of CANARIE for innovative solutions. WOW combines the power of @your side health care (information and management for clients), @your side colleagues (e-learning support for healthcare professionals), and @your side companions (tools for remote monitoring and consultation).

The application of WOW was evaluated in rural and remote settings for both cardiac care and wound care. 'WOW Cardiac Care' combines, for the client, an online learning program about cardiac disease, programmed questions, telehome-monitoring (pO₂, bp, temperature, weight), and access to the specialist. For cardiac care professionals it offers patient management and an e-learning program. Monitoring data is transmitted to a central station, where the nurse trends the data and creates new knowledge (wisdom) that is entered to help with case management discussions and online learning. 'WOW Wound Care' combines digital imagery (of the wound), online assessment or remote access to consultation, patient management, and online learning for the healthcare professional. Again, the data is transmitted to a central station, where the nurse trends the data and creates new knowledge (wisdom) that is entered to help with case management (e.g. new treatment intervention, wound care products), or is used for e-learning needs.

WOW has been implemented in five sites across Canada for wound care and for cardiac care in Ontario only. Implementation is close to complete, and evaluation is still in progress. About 26 nurses and 200 clients (80% wound care) have been involved. Preliminary findings demonstrate improved access to the specialist, increased productivity of the specialist (increasing from 4-5 consults a day, to perhaps 40-50 a day), reduced travel costs (clients and specialist), improved knowledge (online programs for healthcare professionals, as well as better self-care management by the client), promotion of best practice, and overall satisfaction with the innovation from both healthcare professionals and clients.

A functional, effective, and scalable web-based tool has been developed for support of cardiac and wound care patients in their own home. The WOW solution has provided enhanced client and provider support that promotes self-care by clients and application of best practice by providers. As well as traditional lessons learned (need for excellent project management; need for champions; need for pre-, during, and post- implementation training; need for ongoing and adequate technical support), other less commonly cited lessons were the need for a thorough understanding of workflow (to minimize negative perception or impact on personnel), a need for change management support, and the need for dedicated

telehealth personnel to be truly responsive to the programs needs). WOW should be applicable to other patient groups.

What has been accomplished?

- A functional, effective, and scalable web-based tool has been developed for support of cardiac and wound care patients in their own home.

What benefits have been realized?

- Preliminary findings demonstrate improved access to and productivity of the specialist, reduced travel costs, improved knowledge, better self-care management, promotion of best practice, and overall satisfaction of healthcare professionals and clients.

Lessons Learned/Advice/Knowledge for Sharing:

- Excellent project management is essential.
- Champions are still necessary.
- Training is needed throughout (pre-, during, and post- implementation).
- Ongoing and adequate technical support is essential.
- A thorough understanding of workflow is needed before making changes.
- Change management strategies and support are essential.
- Dedicated telehealth personnel are required.
- The solution may be applicable to other patient groups.

Project Partners:

CANARIE and Saint Elizabeth HealthCare.

**3.0 The Diabetes Self-Management Network (DSMN)
Nick Zamora, Optium Digital Solutions Inc. Toronto ON**

The need for chronic care management was again the stimulus for this study. An existing 'expanded chronic care model' for multi-disciplinary care of Type 1 diabetes was selected (DSMN model) that viewed the activities of healthcare organizations as only one integral component of a larger community approach. This project enabled the community based – nurse centered model through adapting it to available technology. The goal was to support the patient or end-user, the family, and the healthcare team, as well as providing data for analysis and standards development.

The fundamental problem being addressed was the lack of timely information to empower decision-making. The target population is typically young (5 – 25 years), lacking incentive or motivation to 'poke' itself for a blood glucose testing or to regulate insulin doses based upon the results. As a result poor control is common. The need is for a mechanism that provides specific behavioural reinforcement, data management and sharing, and facilitates adherence to evidence-based guidelines. The value, beyond quality of life, is reflected in CIHI's estimate of the cost to Canadians of diabetes - \$10 billion per year – a proportion of which could be eliminated through improved patient outcomes.

The project was successful in its technology concept, with patients using their PDA's and clinicians using the web. This allowed greater exchange of information by messaging between the care team and the patient and augmented contact, raising it from every 3-4 months to every few days. As a result direct and timely provision of advice on management

was possible. In addition, collating and trending of their own data increased patients' understanding of their disease, empowering and motivating them.

This patient group liked the PDA's and the intuitive design, requiring little training and an enjoyable challenge when learning the technology. They also liked being allowed to use their PDA for additional purposes, including organization, games, MP-3 functions, MSN/ICQ, and e-mail functions. Communication challenges arose due to the large catchment area (with less reliable telephone lines, variable ISP, and configuration issues). In addition patient travel (summer camp, vacation) created difficulty with PDA charging, IR synchronization needs between PDA's and glucometers, and ISP connection. Glucometer cleaning and battery problems caused resetting of the date / time stamp. Each of these resulted in time-outs and loss of data

A number of lessons were learned, including the need for technology convergence (seamless synchronization between different technologies), and handling of change management issues. Effective training and a dedicated team minimize these problems. Approaching the project as a continuous quality improvement project would have been a better match, since the RCT approach is too rigid and difficult to apply in real-life, with more formative research needs. Overall, the healthcare and societal environment is changing, and becoming more responsive and accepting of investigating and funding new models. However, the lag time between product development and technology adoption is troubling. The DSMN model will be further enhanced, and adapted to management of other diseases.

What has been accomplished?

- A functional, effective, and scalable web-based tool has been developed for support of diabetic patients in their own home.

What benefits have been realized?

- Preliminary findings demonstrate improved access to and productivity of the specialist, reduced travel costs, improved knowledge, better self-care management, promotion of best practice, and overall satisfaction of healthcare professionals and clients.

Lessons Learned/Advice/Knowledge for Sharing:

- Seamless convergence between different technologies is crucial.
- The RCT approach is too rigid and difficult to apply in real-life,
- The lag time between product development and technology adoption is troubling.
- Change management strategies and support are essential.
- Dedicated and trained telehealth personnel are required.
- The solution is applicable to other patient groups.

Project Partners:

CANARIE, Charles H. Best Diabetes Centre, Children's Hospital of Eastern Ontario, Compaq Canada (HP), and IRIS Systems Inc.

D. INNOVATIVE PRODUCT DEVELOPMENT

The technology behind telehealth continues to move quickly, and development of innovative products that transfer the technology from concept to useful reality that meet client needs is gaining in importance. Innovative telehealth companies must manage their portfolio of products and services to respond to, and anticipate, ongoing changes and needs. Strategies that include innovative development of new products, as well as innovative improvement of existing products and services, allow companies to stay ahead of their competition. The projects described in this section exemplify innovative product development in telehealth.

1.0 When it Comes to Health – Evidence Matters! Ofer Allan Avital, Evidence Matters Inc. Montreal QC

Evidence Matters Inc. was spawned from frustration with an inability to manage the explosion of new research and information around drugs and other treatments. As clinicians, the founders of Evidence Matters wanted to practice evidence-based medicine, but not be restricted in choice through lack of current information or difficulty accessing the information. The goal therefore was to synthesize information, interpret data, and highlight specific content for distribution.

The product is a knowledge management technology for drug information and other intervention modalities that is a new generation on-line database. Instead of Medline or Google, you can construct a clinical question on medical therapeutics without typing. An instant meta-analysis of the clinical literature is performed related to efficacy, safety, and cost, and an answer is provided that represents a synthesis of the literature. Only reliable information sources are used (Medline, CINAHL, Cochrane).

Currently no simple tools exist with which to find out the efficacy for many therapies, and the literature is difficult to scan and synthesize. With the Evidence Matters product, no algorithms are used; instead the published data is reorganized so that it can be searched more easily. An assessment of local therapeutic choices can be performed, and information located on effectiveness (survival, disease, satisfaction), safety (deaths, pain, cardio toxicity), and cost. It is also possible to 'drill down' to read article summaries or full-text. Information in summaries is updated weekly or several times a week from the literature. It will be possible to interact in multiple languages, although at this point only French and English are supported.

A variety of users exist for the product, including clinicians, healthcare decision makers (government, managers, and formulary developers), researchers, and patients. Many patients already use Medline, and educated patients are equally interested in up to date information. The benefits to users include access to new information, constantly updated, no typing, and fast and simple to use technology. The stand-alone version requires only a web browser and a PC, and an EMR version is available. The handheld version will be available in the future. The Evidence Matters Server uses open source architecture (Linux, JSP/JAVA, Apache, OODB – object oriented database) and links to the client through the browser.

A demonstration of the product displayed the use of the question wizard through which a question can be posed. Answers are provided in graphic form, as a series of stacked boxes

that reflect the recurrence rate for the response, acting as an effective filter for the literature. Clicking on the box reveals the references relevant to that box. In addition a list of therapies, reoccurrence rates, and further references appear, and it is possible to drill down to the summary, or link to full-text articles. The product is being launched with the oncology package, and although some parts of the product will be available free for trial an annual subscription will be required for the rest.

Two test centers in major teaching hospitals have evaluated the product from this project (libraries in McGill teaching hospitals, and the Research Centre at Harvard Medical School). Responses from both have been very positive.

What has been accomplished?

- A distinct PC-based product has been developed and marketed that provides evidence-based information to the fingertips.
- The first version addresses oncology.

What benefits have been realized?

- Preliminary findings from two respected teaching hospital centres are most positive.

Lessons Learned/Advice/Knowledge for Sharing:

- A broad group of users desire access to evidence based information (clinicians, healthcare decision makers, researchers, and patients).
- The product is being migrated to a mobile format.

Project Partners:

CANARIE and Evidence Matters Inc.

**2.0 Doc 2 Doc - Electronic Patient Referral
Ed Brown, NORTH Network. Toronto ON**

This project identifies an opening for telehealth in the urban environment, and seeks to automate the referral process between family physicians and specialists. The irony is that although patients are ready for electronic health care, providers are not. They have difficulty understanding how it fits into general practice.

The current referral process is disorganized, inefficient and prone to omissions and discontinuities. When referrals are made, the specialist often receives incomplete information, and the family physician is unable to track where their patients are in the referral process. A part of the problem relates to the lack of communication between family physicians and specialists both before and after the appointment date. As a result of this inefficient and ad hoc process, support staff spends considerable time arranging referrals, and preparing, mailing, or faxing patient information.

A solution to this dilemma has been developed, termed the Electronic Patient Referral and Telehealth Consultation Utility (EPRTCUCU). This solution automates the patient referral process, enables secure sharing information between family physicians and specialists, permits instant patient appointment booking, and enables the capture and transmission of digital images and other patient data as an integral part of the referral process, i.e. telehealth. As a result it organizes the chaos that frequently exists, and might even allow

specialists to make a diagnosis based upon the quality and quantity of pertinent and structured patient information they receive.

The EPRTC software was developed by Borland, with beta testing in October 2003, and pilot testing in December 2003. Considerable time was first spent carefully developing requirements, particularly focusing on workflow and making it useful in the physicians' office setting. This process was facilitated through a family practice and specialist advisory group, and through the existence of a core data set in Ontario (minimum data set of information that physicians want to share with each other about the patient).

The referral form is the core piece of the software package, and to simplify the referral process as much as possible, it gathers data from the physician's local patient database and inserts it into the referral form. The physician then selects their specialist of choice, types in the chief complaint, and enters additional data as necessary (e.g. photographs, electronic files). The addition of a voice capability to avoid typing was considered and is an important aspect for busy clinicians. The physician can also hand off the referral process to someone else, have it saved as a draft, and later review it prior to release.

Using the software, a referring physician can create a referral, get an appointment, add data to the referral, track the status of where patient is in the cycle, and answer and ask questions. In turn, the specialist would use the same referral package, review consultation notes, add referral notes, and also answer and ask questions. Only the referring physician, specialist, and office staff can access the database, and being point-to-point simplifies security issues. An audit log maintains data on each transaction.

Doc-2-Doc is the first tool to enable family physicians to track progress of their referrals, and to prevent patients from 'falling through the cracks' as can happen with the traditional referral process. It improves the efficiency of the referral process for both physicians and staff, improves communication, improves quality and content of information exchanged, enhances continuity of care, reduces unnecessary duplication of tests and diagnostic procedures, and may result in more rapid resolution of problems and avoidance of unnecessary consults.

Lessons learned can be summarized through the challenges that impacted the project. These included a long development cycle, the SARS epidemic, and corporate challenges (committed contracts moving on and impacting project flow). In addition, trade-offs were necessary (such as using proprietary components to decrease overall development costs), and infrastructure deployment met with simple but time consuming difficulties (e.g. need for fax lines, computers). Although physicians see the value of Doc-2-Doc, a major challenge was change management of physicians (encouraging automated practice), which took a lot of energy. Whether they get over their inertia and use it could be the problem.

What has been accomplished?

- A distinct software product that supports efficient and secure patient referral from family physicians to specialists has been developed and is ready for market.
- This was described as the first such tool.

What benefits have been realized?

- The patient referral process has been streamlined.
- Unnecessary duplication of procedures and tests is avoided.

- Consistent and adequate patient information is exchanged.
- Unnecessary consults may be avoided.

Lessons Learned/Advice/Knowledge for Sharing:

- A long development cycle resulted from unrealistic and unnecessary software development expectations by vendors.
- Unexpected natural disasters can impact – SARS.
- Corporate continuity challenges arose (contacts moving on).
- Trade-offs necessary (e.g. use of proprietary components to decrease overall development costs).
- Infrastructure deployment was delayed.
- Promoting change management of physicians was exhausting.
- Overcoming physician inertia may be a major problem.

Project Partners:

CANARIE, NORTH Network, Borland, Sunnybrook and Women's College Health Science Centre Innovation Fund, Sunnybrook Family Practice Unit, and Sunnybrook Dermatology Department.

3.0 PPP System Development - Persistent Security: Access Control & Tracking Merv Matson, RightsMarket Inc. Calgary AB

Several approaches to security exist. Repository security retains a record behind a peripheral defense such as a firewall. Channel security or delivery security guarantees that material will travel from source to destination without interception along the way, i.e. protection against hack attacks using an encrypted tunnel. Although hack attacks may have worse consequences, it is not the big problem. Most security breaches occur accidentally through an insider after the information has reached its intended destination (the end user, e.g. physician offices). The Business Information Security Survey of 1998 (National Computing Centre, UK) showed that 70 – 80% of security breaches occurred internally, and that only 6% were deliberate (rogue users). An example might be inadvertently responding to an e-mail by clicking 'reply all' rather than 'reply', when the information being returned is for the eyes of one individual only. The worst aspect of such 'leaky' security problems is that they are often invisible – no-one is aware it has happened until it is too late.

To counteract this, 'persistent security' has been developed by RightsMarket. It goes beyond passwords, access policy, firewalls, and VPN's to fill the current gap in providing total security. It does so by providing access control and tracking for records even after they have already been distributed. Furthermore, persistent security stays with the information, and retains access and tracking control every time and everywhere the material is used. It is a secure document no matter what copies are made, or wherever it is, the integral persistent security component retains control over access. This does not impair the ability to legitimately redistribute information (e.g. to another healthcare provider for a consult), but does ensure continued security for the information. However, it can be expected that a legitimate user may try to share a record with someone who does not have permission to access it. How can you enforce access control after distribution?

This has been addressed by incorporating the 'Policy and Peer Permission' concept into persistent security. The concept is a mechanism that handles permissions based on predefined policy and peer instructions. Policy permission to redistribute is obtained using

automatically interpreted policy, such as a patient's embedded instruction that "my designated caregivers can see all of my records except ...". Peer permission to redistribute is controlled by a peer (e.g. family physician) who, with patient consent, sends medical records to a specialist with specific permissions associated with it, thereby keeping control of that record. In this way the combination of persistent security with policy and peer permission can protect a record against any individual who does not have the documented right to access it. The security settings for a document go with that record always – wherever it is, and can even be changed after distribution, e.g. allowing viewing only but preventing printing or screen capture.

An important aspect of persistent security and policy and peer permission is their ability to address the main requirements identified in the recently enforced PIPEDA legislation. This includes organizational accountability for personal information, and the need to protect against unauthorized access, disclosure, copying, use, or modification. Persistent security uses technology to retain control even after delivery, specifically authorizing and tracking use every time, everywhere.

Lessons learned include the need for enhanced security beyond simply delivery security, and the need to comply with new privacy laws, both of which are accomplished with persistent security.

What has been accomplished?

- Distinct software products have been developed that ensure persistent security of sensitive information, even after it has been distributed.
- This was described as a unique capability.

What benefits have been realized?

- Complete protection of sensitive patient information can now be accomplished.
- Compliance with new privacy laws is now possible.

Lessons Learned/Advice/Knowledge for Sharing:

- Security protection must extend beyond simply delivery security
- An immediate need exists to comply with new privacy laws.

Project Partners:

CANARIE, RightsMarket, University of Calgary, Ottawa Heart Institute

E. BEGINNING TO END (ROI, Outcomes, and Tools)

Behind the technology of telehealth lies the need to establish its value through the design and application of various models related to business cases, implementation, and evaluation. Such models also require the development of simple tools that can be universally applied to develop the evidence-base around telehealth. The projects described in this section each refer to the development of models and tools related to telehealth.

1.0 A Readiness Model for Telehealth

Can We Pre-Determine How Prepared 'Communities' and Users Are?

Penny Jennett, Global e-Health Research and Training Program, Health Telematics Unit, University of Calgary. Calgary AB

This study aimed to construct and define the “essence” of telehealth “readiness” for rural and remote communities, and to present a framework that could be used by rural and remote communities to assess their state of readiness for telehealth. Past evidence highlights that investing in ICT solutions, when communities are not ready, repeatedly leads to failure to mainstream (e.g. large-scale IT projects exhibit a 30% or greater failure rate). The work was grounded in lessons learned from northern BC and the Yukon. The framework and resultant tools are now being used in the Alberta SuperNet Initiative. This Initiative is placing broadband infrastructure into rural and remote communities in that province.

An extensive literature search around readiness showed several definitions exist, each of which tied readiness to successful change. The change process has also been described in the literature, and is viewed to proceed through several states: from the status quo to a state of unfreezing, to a state of moving (change), and to a state of re-freezing to create a new status quo. It is the first step, from frozen to unfreezing, that is impacted by readiness. If readiness assessment is not performed appropriately, then difficulty will be experienced in unfreezing from the status quo.

To determine what influenced readiness, several methods of data collection were used, including consultation with experts, key informant interviews, focus groups, and awareness sessions for the communities. The latter included, telehealth posters, videos, and live demonstrations back to Calgary.

A qualitative approach was taken for data collection and analysis. Specifically, interviews and focus groups were audio taped, transcribed, and analysed for themes. Prominent themes within the data included core readiness; assessment of risk; projection of benefit; structural readiness and responsiveness; education and awareness; and intra and inter-group dynamics. Several “communities of interest” were identified, each of which had their own readiness perspective. The “communities” identified were organizational, patient, public, and practitioner. Sitting at the center of each of these was ‘community readiness’ which looked at the readiness of all other components. In addition, four types of readiness for each community were identified: 1) Core Readiness (identification of a need and dissatisfaction with the status quo); 2) Engagement Readiness (questioning stance and risk assessment); 3) Structural Readiness (building of required structures and supports); and 4) Non-readiness (a lack of need or failure to recognize need).

The study has accomplished development of precise definitions around what is meant by readiness, and has created tools that effectively place the power into the hands of the community to determine its own readiness. Through this, several benefits are realized, including the ability to accurately describe and assess readiness at several levels. The tools have also been disseminated in a global manner, including with colleagues in Australia, UK, and the EU.

Lessons learned focused on the need for a team and collaborative approach, both locally and nationally – partnership is crucial. Having local research assistants and community volunteers helped, and visiting with them gave valuable and intimate perspective and built rapport and trust. All of the demonstrations and awareness sessions were facilitated locally. Nationally, key informants were selected from across the country, as well as CANARIE and Health Canada. Strong, and central project management was required. Perhaps the most important lesson learned was – always assess community “readiness” first. It cannot be assumed that people are ready for telehealth. The tools developed through the project are

now available for communities to use to help them to determine whether readiness exists to mainstream telehealth solutions. The tools continue to evolve and feedback would be welcome.

What has been accomplished?

- The area of readiness has been clearly explored.
- Categorisation and definition of key areas of readiness have been provided.
- Specific readiness tools have been developed and broadly disseminated.

What benefits have been realized?

- The tools have been demonstrated to be of value in practical settings.

Lessons Learned/Advice/Knowledge for Sharing:

- A team and collaborative approach – partnership - encompassing all stakeholders is essential.
- The availability of local participants in the research enhances readiness and enriches understanding and trust.
- Broad input is essential to understanding key issues.
- Readiness is an essential component to the success for telehealth initiatives, and must be addressed.
- Strong central and site project management in multi-partnered initiatives is crucial to success.

Project Partners:

CANARIE, Health Canada, University of British Columbia, University of Calgary, Health Telematics Unit, University of Northern British Columbia

**2.0 Report of ‘e-HealthCare: What Constitutes Return on Investment?’
Richard Scott, Vice-President Canadian Society of Telehealth. Head Office –
Kingston ON**

A number of organisations provide funding for the preparation of reports for conferences, workshops, and other meetings. This is often considered to be support for the activity as much as for the report. As a consequence, little investigation has been conducted to determine the value of such reports. In order to exercise due diligence, CANARIE not only funded preparation of a report of the 5th CST Annual Conference held in Vancouver during October 2002, but also provided funding for conduct and analysis of a survey to determine the value of their investment. This project was intended to answer the question: “Is there value to the broader telehealth community in preparing reports of CST conferences?”

To answer this question, the conference report was prepared and distributed as an e-mail attachment by the CST Head Office to the membership of CST (234 individuals). Two weeks later, a follow-up survey was prepared and distributed to the same group. The survey collected data on demographics, and the format, timeliness, use, utility, and value of the report. A response rate of 13.3% was achieved, with respondents from various sectors: public (33%), private (23%), professional (20%), and academic (10%), with no response in 14% of returned surveys.

Responses identified that distribution as a PDF document was uniformly acceptable, and that to be useful the report needed to be distributed between 3 to 6 months after the event.

All but one respondent opened the attachments. Of the remaining 97% of respondents multiple responses indicated that 17% read the report, 30% reviewed it, and 73% scanned it. Most respondents indicated they filed the report for reference (43%), and 73% shared the document with one or more colleagues. Most respondents said they would use the report for reference (33%), for research (25%), or for information with regard to policy (21%) or education (21%). In response to the overall importance of the report, a total of 87% indicated it was either important (60%) or very important (27%). Additional commentary highlighted three specific values of the report: it contained what was actually said during the presentation (rather than what it was intended to say as described in abstracts), it provided a good understanding of the content from concurrent sessions it was not possible to attend, and it provided a lasting aide-memoire.

The need for stimulating greater response was identified as a limitation, and it was suggested a web-based 'click and send' survey might be better. This project demonstrated there is good return on investment for the production of reports such as this. The report was of good value, well used, and utilized for a wide variety of purposes.

What has been accomplished?

- Evidence-based justification for support from agencies in funding preparation of reports from conferences has been provided.

What benefits have been realized?

- An understanding of optimal format and timing of dissemination of conference reports has been described.

Lessons Learned/Advice/Knowledge for Sharing:

- Distribution in PDF format is universally acceptable.
- Reports must be prepared and disseminated within 3 to 6 months of the event.
- Reports find broad application as an aide memoire and in supporting research, education, and policy debate.

Project Partners:

CANARIE and the Canadian Society of Telehealth

3.0 Outcome Indicators – NTOIP Speaking with One Voice?

Richard Scott, Global e-Health Research and Training Program, Health Telematics Unit, University of Calgary. Calgary AB

The need for this project was based upon the argument that healthcare resources are finite, and already being redirected towards e-health solutions. To be confident this is an appropriate strategy requires that we facilitate critical thinking and critical decision-making. This in turn requires that we have high quality and consistent scientific evidence of the 'value' of e-health solutions. Such an evidence base does not exist, and to develop it swiftly requires consistent use of accepted and defined outcome indicators. NTOIP (**National Telehealth Outcome Indicators Project**), conceived in 2001, was designed and implemented to stimulate this process. (Website: www.ucalgary.ca/ntoip)

The first stage in NTOIP was to determine what we know about telehealth outcome indicators within the broad categories of quality, access, acceptability, and cost. A systematic review of the literature identified what outcome indicators and definitions exist.

This information was collated and assessed in the NTOIP Information Document, and supplemented through development of clear outcomes related definitions for: e-health *outcome*, e-health outcome *indicator*, e-health outcome *measure*, and e-health outcome *tool*. In addition a conceptual framework (telehealth outcomes development (TOD) framework) was presented to guide the outcomes development process.

The second stage was to identify Candidate Outcome Indicators (COI's). This was achieved through an invitational workshop that took place in June 2003. These COI's were subsequently reviewed, refined, and described within a structured framework, and then moved to the third stage – a web-based consensus process. This is being undertaken at this time, and will be complete by May 2003. Nine COI's have been developed for quality, 6 for access, 7 for acceptability, and 10 for cost. During this process the COI's are presented on the web for the broader telehealth community to look at and critique. Each indicator proceeds through three stages of development (Proposed, Tentative, and Approved) based upon feedback received.

In addition, again based upon feedback, the top 3 indicators in each category will be identified to provide the 'core set' of 12 approved telehealth outcome indicators. Once this point is reached, these will be considered the final product of NTOIP consensus based and national "outcomes guidelines". An important aspect of NTOIP is that it is not proscriptive. It does not restrict the evaluation process undertaken by any group; rather it provides a smorgasbord of outcome indicators from which to choose. Consistent selection of some indicators from this group will facilitate us moving forward together and more swiftly towards building our required evidence base. Significant dissemination efforts have been undertaken based upon a need for awareness identified by workshop participants. This includes two awareness workshops (CST, October 2003; COACH, May 2004).

Nearly 2 years ago there was no regional, provincial, or national agreement on which quantitative or qualitative measures are appropriate and most valuable when evaluating telehealth applications. Furthermore, there were no accepted definitions for those indicators and measures being used. Now 1½ year into the project – things are beginning to change. Feedback has indicated the Information Document and Workshop Report developed through NTOIP are being used in various organizations across Canada.

NTOIP's primary lesson learnt is that 'it ain't easy'. Seeking, defining, and gaining broad consensus on outcome indicators is difficult. Focus has to remain on the ultimate goal that will be advantageous to us all – building a strong evidence base more quickly. Compromise is required. NTOIP has opened many opportunities, it has: promoted systematic identification and definition of telehealth outcome indicators; developed sets of outcome guidelines; identified areas where indicators are lacking; enhanced reporting of telehealth evaluations; promoted a mechanism for direct comparison between evaluations; established telehealth outcomes benchmarks; all of which will better inform policy decisions.

Applications have been submitted for additional outcomes related funding, and a particular proposal for a virtual network across Canada termed ADOPTS (Agreeing on Defined Outcome Parameters for Telehealth Solutions) is being developed. The goal of NTOIP (to identify and define a core set of generic outcome indicators for evaluation of telehealth solutions) remains a unique undertaking; no other country has looked in a systematic way at evaluation outcomes. Canada is in the lead in this area, and the momentum built should not be lost.

What has been accomplished?

- The area of telehealth outcomes has been clearly explored.
- Key definitions around e-health outcomes have been provided.
- Information about outcomes has been broadly disseminated.
- A unique web-based approach to gaining broad consensus has been designed and implemented.
- Specific outcome tools have been developed and broadly disseminated.

What benefits have been realized?

- Based upon feedback, the tools and information document have been acknowledged and applied in several telehealth settings.
- The broader telehealth community has been engaged in a consensus process around a key issue.

Lessons Learned/Advice/Knowledge for Sharing:

- It is not easy to gain agreement within the telehealth community.
- Compromise on the part of all stakeholders is essential if progress is to be made.
- Broad input is essential to understanding key issues.
- The identification, definition, and consistent application of agreed upon outcomes is an essential component to the success of telehealth initiatives, and must be supported.

Project Partners:

CANARIE, Richard Ivey Foundation, Health Telematics Unit, Atlantic Health Sciences Corporation.

F. THIRD GENERATION TECHNOLOGY

Technologies continue to evolve to meet the needs of health and industry stakeholder groups. This Session welcomed presentations developing and testing third wave technologies, e.g. grid computing, web services, and central repositories.

1.0 Integrated Information Management Platform Across Canada (iIMPAC) The iCAPTURE Centre and Information Management Challenges Marilyn Andersen, iCAPTURE – UBC and St. Paul’s Hospital, Vancouver BC

The iCAPTURE Centre is located at the University of British Columbia. The Centre generates and uses data on cardiovascular and pulmonary research. At the Centre, an integrated information model called the iQ Engine has been designed to address the challenge of “expanding, voluminous, diverse, complex, and various formatted data sets” that are generated in wet laboratories, clinics and the community. The pilot objectives were to design and implement an information system capable of handling data challenges, providing processing speed, and “integrating interdisciplinary information for innovative investigation, interpretation, inspection, and querying”, as well as data computational mining and analysis tasks.

Specifically, iCAPTURE Centre data sets include: imaging, cell analysis and phenotyping to understand response, repair, remodelling and genetic/recombinant events related to

cardiac and pulmonary disease. Presently the iCAPTURE Registry system (i.e. integrated database) contains data and images from humans and models. The data is composed of:

- Core 1: Molecular phenotyping (e.g. patterns and quantification of proteins and genes).
- Core 2: Ultrastructural imaging (e.g. high resolution images).
- Core 3: Dynamic Cellular Imaging (e.g. real time images in cells and tissues).
- Core 4: Organ pathophysiology and imaging (e.g. “in-live” images of heart and lung function).
- Research models (e.g. cell models, conventional and genetically modified models).
- Foundations of excellence (e.g. quantitative data of images).

The types of research that can be done using the database include: pathophysiologic, functional, gene expression, polymorphism detection, linkage analysis, and association studies. The database contains research regarding complex genetic diseases such as: atherosclerosis, valvular heart disease, asthma, chronic obstructive pulmonary disease (COPD) and systemic inflammatory response syndrome.

The architecture of the IQ Engine in the pilot focused initially on a vertical slice as the overall strategy. The validation of the model was conducted by characterizing features of rheumatic mitral valves.

The pilot project has now proceeded to “the information management platform proposal entitled iIMPAC: Integrative Information Management Platform across Canada”, and has been submitted to the Canada Foundation for Innovation for funding approval. iIMPAC will contain clinical, laboratory and sociodemographic patient data and feature established and innovative analytical tools. iIMPAC’s objective is to provide an adaptable and unique Canadian research tool with the potential to transform research across Canada.

What has been accomplished?

- The design and validation of the integrated information model concept.

What benefits have been realized?

- A demonstrated “integrated” information system for cardiovascular and pulmonary research.
- An improved research analytical tool.
- Increased collaborative relationships between partners and geographically dispersed team members.
- The capability to generate hypotheses and provide analysis.
- An integrated data platform for national application.
- “Improved accuracy, timeliness and specificity of risk assessment, diagnosis and treatment.”
- Cost benefits.
- Potential improved preventive outcomes/strategies.

Lessons Learned/Advice/Knowledge for Sharing:

- There were challenges from the data resulting from complexity, diversity and volume. Challenges were present in “database management, computational/processing speed and corresponding analysis tasks”.
- Difficulty to find people with scientific strengths and to train them on the system.
- Need for secure architectures for access and patient data protection.

- Addressing the issues of the “semantic web” (i.e. international data capture).

Project Partners:

CANARIE, The James Hogg iCAPTURE Centre for Cardiovascular and Pulmonary Research, University of British Columbia, St. Paul’s Hospital, Vancouver BC, Canada Foundation for Innovation, and British Columbia Knowledge Development Fund.

**2.0 Distributed Content Networking Systems (Submitted Post-Workshop)
Mo Kermani, Bycast Media Systems Inc, Vancouver BC (Unable to Present)**

Practice and experience in clinical deployments of storage grids for the transmission and storage of diagnostic imagery

As the volume of digital medical images grows and access requirements increase, the centralized approaches to image storage and archiving become increasingly impractical to scale and operate. To address this issue Bycast has developed a ‘fixed content’ storage system that applies next generation grid-computing solutions – the Bycast StorageGRID™. Fixed content is information that does not change after creation, such as medical images (e.g. MRIs, CTs, x-rays) and electronic business documents (e.g. emails). This approach addresses the economic and logistical challenges associated with the storage and distribution of very large volumes of image data throughout geographically distributed environments. It provides rapid access to information, lowers storage costs, and permits redundant storage and intelligent information lifecycle management.

BC Cancer Agency (BCCA), a multi-facility healthcare organization responsible for all cancer care in the province of British Columbia, wanted to store and protect all of their cancer related images and make them available throughout multiple facilities as part of the electronic patient record. BCCA deployed the Bycast StorageGRID MultiSite™ across five facilities to form a 14 Terabyte archive that is linked with the electronic medical record and acquires studies from internal sources (e.g. PACS) and five external hospital sources (e.g. PACS). More than 1,000 clinicians use the system.

What has been accomplished?

- The deployment of a ‘fixed content storage system’ (i.e. a unified multi-site archive that enables rapid access to current and historical imaging studies regardless of location).

What benefits have been realized?

- Increased efficiency and enhanced patient care through easy and seamless access to diagnostic images from the existing EPR.
- Reduced costs through the deployment of an open standards-based solution supporting simple scalability.
- Greater compliance through the deployment of a fault tolerant ‘self-healing’ solution that is secure and ensures information integrity and availability.

Lessons Learned/Advice/Knowledge for Sharing:

- It can be expected that laws and regulations may begin to specify record availability, integrity, authenticity, retention period, and system audit capability.

Project Partners:

CANARIE, Bycast Inc., BC Cancer Agency

3.0 Community Health Information Network/CCAC Louise Liu, Waterloo Region Community Care Access Centre, Waterloo, ON

Community Health Information Network (CHIN) is a secure, electronic internet-based information exchange mechanism, with web-based services, that is used to exchange client related information among stakeholders in a timely fashion (from hospital admission to professionals who serve clients in their homes). CHIN was designed to address problematic issues such as: client information that was held in different parts of the health services continuum, duplicate information, the under-funded/utilized information technology issue, no standardized data elements, multiple data exchange mediums, delays, and loss or fragmentation of information. The CHIN concept was a system that provided: 1) secure connectivity for confidential client information exchange; 2) interface consistency for all users regardless of location and technology; 3) improvement of services to clients through timely information exchange; and 4) new data sharing opportunities with health care stakeholders. CHIN has evolved from six pilot projects and has been a successful telehealth model.

CHIN today has 42 stakeholder organizations and over 180 users accessing it daily. It uses a public key infrastructure, Smart Systems for Health Agency secure network, common interface to access different databases of various organizations, and an intelligent e-form (legal document). CHIN's functionality includes:

- electronic billing (50 files/week from 11 providers)
- equipment ordering (1000 equipment orders/month)
- long term care wait lists (on-line placement wait list)
- referral processes (service order/plans completed on-line by Case Managers and sent electronically to Service Providers).

What has been accomplished?

- Inter-organization information exchange of client information within an environment of non-integrated information systems.
- Growing interest and support for the solution among other Community Care Access Centres and stakeholders.

What benefits have been realized?

- Improved efficiency of patient services delivery.
- Secure, reliable, relevant and accurate information exchange.
- Instantaneous messages.
- Legal documents can be exchanged.
- Time saved from direct retrieval and input of information from a database.
- Streamlined administrative procedures.
- Future benefits arising from CHIN: a more efficient platform for stakeholders to exchange client data; development towards a common standard; economic use of increasingly scarce health care dollars; and improved services to clients.

Lessons Learned/Advice/Knowledge for Sharing:

- Have clear objectives.
- Success is achieved in small steps.
- Training is critical.
- Manage the change process.

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- Build in privacy & confidentiality protections into the solution.
 - Technology advancement and business processes must work together.
 - Business Perspective: It is important to “obtain organizational commitment, review business processes, and establish closer business relationships”.
 - Legal Perspective: It is important to “develop agreements and conduct privacy impact assessment”. Establish required policy structure.
 - Technology Perspective: Use available technology innovatively to find solutions to meet business needs.
 - People Perspective: Focus “on staff as integral to the change process, success was achieved in small steps and training was critical”.

Project Partners:

CANARIE, Waterloo Region Community Care Access Centre, in partnership with the Ministry of Health and Long Term Care, contracted Service Providers, Long Term Care Facilities, hospitals, family physicians, and other health care providers.

4.0 Dossier Réseau Informatise en Oncologie (DRI-O-Q) Breast Cancer Database, HABILIS – Putting Information in Context Andrew Grant, University of Laval, Laval QC

The objective of HABILIS was to develop a prototype software tool that was web-based, flexible, and adaptable, as well as had the generic ability to deal with bits of information in an object-oriented way for different sources and contexts. The HABILIS project was a prototype designed for application to oncology and cardiology. These two fields have similar characteristics: diseases with a long trajectory; acute and chronic care components; elements of community based and continuity of care; complex diseases with strong hereditary elements; and both have major prevention and multi-disciplinary care management aspects. In addition, there is extensive research and on going advances in diagnostic and treatment in these two domains.

The dynamic tool developed can access, share, and assemble data tailored to different users, contexts, and views required in various clinical situations. Furthermore the clinician researchers required:

- Project control (i.e. ability for the researchers to modify project structure without reliance on programmers)
- Data access and sharing (i.e. secure data sharing; sharing only part of the data)
- Extendable, secure and stable system (i.e. audit trails; levels of security access; ability to add/remove item fields; multi-level validation to reduce data entry errors)
- Simplicity (i.e. both beginners or experts can use the system with ease; standard interfaces)
- Flexible reports (i.e. output data in any format such as graphics or text; save query request for re-execution; fast and easy access to reports)
- Generic interfaces (i.e. user friendly interface builders; “for a multi-centric research, be able to have own output interfaces”)

What has been accomplished?

- The initial development, testing, and prototyping of the open source HABILIS software prototype for sharing and partnering, has occurred.
- The architectural component has been developed.
- Application screens will be available in the next few months, as will prototypes for nurse, physician, and home use.

What benefits have been realized?

- Collaboration between partners.

Lessons Learned/Advice/Knowledge for Sharing:

- Modifications to the prototype to include portability and wireless application.
- Current development of the tool to include patient data.
- Need for open collaboration.

Project Partners:

CANARIE, University of Laval; University of Sherbrooke; Quebec Cardiology Network; Cybersanté Quebec; Clinical e-Science Framework (UK) project – Royal Marsden Hospital and UCL.

Section II: Strategic Initiative Program (SIP)

Two projects were funded within the CANARIE Strategic Initiative Program. One two-day round table Initiative assembled Canadian representatives to develop guiding principles and define a proof-of-concept project for an integrated e-health model. The second was a three year EU Canada e-health Initiative to promote EU Canada collaboration in health telematics systems and services.

1.0 The Way Forward: “From Telemedicine to E-health” Round Table Erin Keough, TETRA, Memorial University of Newfoundland, St John’s NF

A two-day round table session assembled representatives from professional associations, health boards, the federal government and Newfoundland governments, private sector, education sector, community leaders, consumers, and advocates to:

1. “develop a set of guiding principles on how to maximize the benefits of the uses of ICT’ in health care and health education, and”
2. facilitate a discussion on how to apply those principles in practice by defining a proof-of-concept project that would explore an integrated e-health model. This model would include the full continuum of care, business transactions, education, etc.”

Three key note speakers addressed: 1) the changes the Internet is having on the health system; 2) the potential impact of information on medical school curricula, business models, goals and mandates; and 3) change management approaches that would facilitate organizational change. In addition, five multidisciplinary breakout groups were tasked to: a) create a framework; and b) define essential components of a proof of concept telehealth project that could be implemented in an integrated e-health system.

“Home delivery”, rising consumer expectations, interoperability facilitation, and interjurisdictional collaboration were discussed. Ten “E”s in Health: “efficiency, enhanced quality, evidence based, empowered consumers, encouragement partnership, education, enabling information exchange, extending scope, ethics, and equity were outlined. The importance of training that would transfer to practice was noted. Organizational change, analysis of organizational reality, identification of key stakeholders, clarification of problem(s), and creating a new context were referenced.

The breakout groups were given an initial model of an integrated health care system with the following components: systems and supports; technology; delivery; integrated health care (core theme); health education; and research and development. Developments from the model would be advanced research, telehealth and the electronic health record. The Groups discussed:

- “Essential elements: ubiquitous networks, EHR, R&D, and patient centric /needs driven.
- Drivers: health professionals, consumers.
- Intermediary Outcomes: properly functioning and supported multidisciplinary health teams, research.
- Barriers: under investment in ICT, government policy, tendency to rush to ICT solution, weak implementation of team process”.
- The suggested framework for proof-of-concept that evolved from the Groups included:

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- 1) Critical Success Factors: community involvement, consistency with existing strategy, continuum care and business, needs based, financially viable – incremental (5 yr) implementation plan / sustainable outcomes, effective human resource strategy/appropriate training, commitment to evaluation, and change management/manage expectations.
 - 2) Issues for Government: policy, just in time information for all, proactive in supporting infrastructure, continue implementation of EHR, create online 24/7 systems, create new costing/funding models, structure for cross-jurisdictional activity and support care closer to home.
 - 3) Issues for Institutions: professional schools, care closer to home, support team base delivery, support community nurses, real time test results to patients, inclusion of patient/family in process, training for patients/family and information and professional development for the health team – Just in Time and synchronous.
 - 4) Issues for Individuals: self management, point of care home not physician's office, accept technology base interactions, establishing trust in new model, and accepting community based treatment.

What has been accomplished?

- The creation of a framework for a proof-of-concept project that could be implemented to demonstrate an integrated e-health system.
- Identified essential elements, drivers, intermediary outcomes and barriers to an e-health system.

What benefits have been realized?

- Increased communication and collaboration between participants.

Lessons Learned/Advice/Knowledge for Sharing:

- The key to success is change management and not technology.
- The need for multidisciplinary collaboration.
- The need for funding for sustainability
- Aligned policy is required

Project Partners:

CANARIE, Telehealth and Educational Technology Resource Agency (TETRA), and Memorial University of Newfoundland.

2.0 EU-Canada e-Health Initiative

Dr. Penny Jennett, Project Lead, Head, Health Telematics Unit. Calgary AB

This EU-Canada e-Health Initiative was approved and ran from February 16, 2001 to June 30, 2003. Its goal was to promote EU-Canada collaboration in health telematics systems and services. Its major objectives were to facilitate, between the two partners (EU and Canada), the transfer of knowledge; share best practice; cultivate networks and linkages; identify areas of shared priorities; encourage collaborative R&D; and to identify ways that the Groups might optimally work together. The Initiative players identified six priority areas: 1) Telehealth and Knowledge Transfer, 2) E-Home-Care, e-Health, e-Care, 3) Trustworthy Personal Health Information, 4) Integration of Telehealth into Health Care Delivery System, across the continuum of care, 5) Rural, Remote and Northern Telehealth, and 6) Evaluation, Best Practices, Business Case.

Events occurred in the European Union and Canada to achieve the Initiative's Goal. These include: working groups, meetings, workshops, and the establishment of a Secretariat office and web site. Specifically, six workshops were held on the following topics: 1) Self-Care; 2) Tele-Home Care; 3) Privacy Protection; 4) Continuing Medical Education; 5) Diabetes Management Systems; and 6) e-Health in Remote areas. Further, activities specific to conferences, workshops and missions centered on: 1) market opportunities, 2) investment indicators, 3) tele-home care, 4) telehealth to support workplace learning in care delivery, and 5) Northern Dimension applications.

An evaluation of the Initiative, involving participants of the Project's Working Groups and events, Project partners, Advisory Committee members, as well as Administrative arm representatives, was conducted. In addition, future opportunities and next steps were outlined.

What has been accomplished?

- A Canadian model (Research and administrative arms) that could serve as a foundation for possible future European Union Canadian ventures.
- Six established EU-Canada Working Groups in the areas outlined above
- Reports from each Working Group, as well as all other activities
- A number of White papers

What benefits have been realized?

- New research collaborations
- White papers (e.g. self care; privacy and protection in e-pharma)
- Personal linkages, new partnerships, networking
- Ongoing Missions
- Web linkages (<http://www.stakes.info/eu-can>)
- Greater understanding of mutual collaborative possibilities

Lessons Learned/Advice/Knowledge for Sharing:

- Clear ongoing bilateral communication among all partners is essential
- Do not commence work until all parties have signed contracts
- Address Secretariat (administrative) and Research activities through separate tracks.
- Ensure funding is in place prior to commencing activities and that all transactions by all parties are completed by the agreed to Project termination date.

Partners:

Canadian: Health Canada, Industry Canada, CANARIE, Canadian Society of Telehealth, and the University of Calgary, Telehealth Program. *European Union:* European Commission Directorate General Information Society (DG INFSO), and the European Union Commission Directorate General External Relations (DG Relex). An Advisory Committee comprised of Canadian and EU members oversaw all aspects of the Project.

Section III: Special Presentations

1.0 Infoway's Telehealth Investment Strategy

**Nancy Desormeau, Vice-President, Communications, Information & Adoption;
Program Director, Telehealth, Canada Health Infoway**

This was the first public presentation of *Infoway's* Phase 1 Telehealth work. A promotional video highlighted the importance and anticipated impact of using information and communications technologies to improve efficiency, cost effect access, quality, and safety of care in Canada, which is considered a pioneer country in the area of telehealth. The vision of *Infoway* is for an increasing range of healthcare services, expertise, and information delivered effectively through a set of expanding, sustainable telehealth networks, interoperable within and across Canada. Focus will be given to governance, enhancement of support for users and clinical services, technology, and management and operations.

Federal, Provincial, and Territorial Deputy Ministers of Health, who are the members of *Infoway*, had noted that there were many pilot projects and were concerned about their financial sustainability, so they asked that a firm strategic plan for telehealth in Canada be developed. To determine this strategy, the 30-year history and current state of telehealth in Canada was assessed. From *Infoway's* perspective, telehealth is a "service delivery channel that uses advanced information technology to offer health care services over distance".

Historically, pilot projects that tested the use of telecommunications technology were conducted 1975–1995. Since 1997 about \$1B (\$500M federal funds plus matching provincial funds) has been invested in 51 Telehealth "pilots" and site installations. The Federal funds came largely from three funding programs (Health Transition Fund (HTF), Health Infostructure Support Program (HISP), and Canadian Health Infostructure Partnership Program (CHIPP)). These programs have involved nearly one-third of currently implemented telehealth sites in Canada. Investments were handled through one-time, project-based, grants and contributions. Most grants supported technology infrastructure (e.g. referral nodes, enhanced range of clinical services, provider networks) or client, provider and clinical services infrastructure (e.g. architecture, broadband network, telecommunications network, security, hardware and software, and maintenance). Very little funding has gone to governance and management infrastructure (e.g. accountability, standards, leveraging other investment, strategic planning frameworks, policy frameworks, and evaluation frameworks). More recently, provinces have begun investing in telehealth call centres for triage, advice, and referral to other resources and services. Infrastructure investments to support all of the above activities have involved various players, including Health Canada, Industry Canada, Canadian Space Agency, CANARIE, and telecommunications firms.

In terms of status, it was noted that little true integration of telehealth into mainstream healthcare systems has occurred. Indeed, evidence was provided that showed despite the significant investment, telehealth in Canada remains fragmented, with low coverage and usage, and low adoption rates by providers. These disappointing features were highlighted when considering that, at best, an estimated 10-15% of Canada's 4,264 rural and remote communities have Telehealth coverage of any kind. Constraints associated with interoperability and integration issues, absence of national protocols, and lack of integration

with the EHR were contributing factors. However, individual telehealth networks remain at a relatively early stage of development, and they offer an increasing range of healthcare services, expertise, and information. Some show evidence of sustainability and are interoperable within and across some jurisdictions in Canada. Telehealth currently enables care in several settings: hospitals, physicians' offices, clinics, long term care facilities, laboratories, community centers, schools, homes, and the workplace. It is anticipated that telehealth will continue to service patients and families, provide socio-economic benefits to the community, increase access for local provision of services, and offer cost benefits to organizations.

Several lessons were learnt from the review and analysis. For example, issues with interoperability, scheduling and management hinder clinical service delivery, and an extensive technology infrastructure is not enough. Full functioning is fostered through balanced attention to governance, management, technology, and adoption strategies at both the local and referral sites. Change management and community engagement (particularly elders) is essential for successful introduction of telehealth to First Nations communities. Higher utilization will only be achieved when: sessions are easy to schedule and conduct (requiring rigorous resource management and automated scheduling); clinical information is reliable, secure and simple to access and share (requiring interoperability standards, and integration with EHR and administrative systems); telehealth networks are well-managed, administered; and tailored to meet the unique language and cultural needs of communities; and physicians are reimbursed and actively engaged, educated, and encouraged to join provider networks. An environmental scan showed that Canada was very similar to other countries (U.S., UK, Australia, Scandinavia, China, Mexico, Argentina, and Brazil) in terms of the issues faced.

Key future trends that will impact telehealth in Canada include: an aging population and increase in chronic conditions that will continue to drive demands on the health care system, emerging technologies that will require higher bandwidth and faster speeds, continued lag of policy issues behind technology growth, and a continued search for strategies that enhance efficiency and effectiveness in the health care system, while clients continue to demand access to quality care.

The intent of *Infoway's* Telehealth Program is to address these issues and trends by leveraging and expanding current telehealth activity through strategic investment. *Infoway's* vision for telehealth in Canada is for "a broader range of health care services, expertise and information delivered effectively through a set of expanding, sustainable Telehealth networks, interoperable within and across jurisdictions in Canada". The first phase of *Infoway's* Telehealth program will involve investments in four key areas: Technical standards, scheduling system requirements definition, enablers and investment stimulus. This will be done in order to validate the analysis and then further recommend investment opportunities.

Four basic funding strategies were identified by *Infoway*: the simple funder (fund and ignore), the strategic investor (invest, advise, and monitor), the intervener (work alongside and take over if needed), and the developer (write code and build modules). Of these *Infoway* has selected the Strategic Investor role, and will: co-invest together with its partners, be involved in how the project is executed, and actively monitor progress and the quality of deliverables to ensure that the final product can be leveraged, as described in their 2003/2004 Business Plan. Thus, *Infoway* will work through the Ministry's of Health in all of the jurisdictions to support its 6 approved programs of which telehealth is only one

(Laboratory Information Systems, Drug Information Systems, Diagnostic Imaging Systems, Registries, Infostructure, and now Telehealth). Provinces and Territories will inform *Infoway* which of the programs represent a priority to them (it is anticipated these priorities will change year to year). In this way *Infoway* gains a clearer understanding of where to invest in further development of established solutions that can then be leveraged and redeployed elsewhere.

Infoway and the jurisdictions both gain the benefit of co-investment and partnership (risk sharing). Plans will be developed with jurisdictional Ministries, projects will be jointly identified, a project charter for the project conditions will be set up, and *Infoway* will flow or withhold funds depending on the deliverables. Each jurisdiction will cost share, and will be responsible for one-time and ongoing operating costs. In addition, jurisdictions will be responsible for clinical data acquisition, ongoing operations, maintenance; and system enhancement (hardware/software, servers etc.) Individuals looking for support for a telehealth initiative were advised that the jurisdiction in which they reside needs to have identified telehealth as a priority.

The aim of *Infoway's* investment in telehealth is threefold. First, to *address and resolve* operational issues in existing telehealth provider networks by optimizing their governance, management and operational capabilities. Second, to *integrate* with EHR and administrative systems by deploying technology solutions that are interoperable, support integration and the use of technical standards. Third, a goal is to *stimulate* investment to expand Telehealth coverage, by leveraging investment by the public sector, employers, and third party payers.

It was concluded that there is a strong desire to make telehealth a viable, sustainable service delivery channel. Currently there is low penetration in terms of enabled communities, low uptake by providers, and limited usage of existing networks. These deficiencies impact the ability to make the case for sustainable funding. As a consequence, it is necessary to immediately address these issues. Doing so is complicated by the many players involved, each with mandates that touch different elements of the infrastructure necessary to manage telehealth. These include telecommunications infrastructure providers and vendors, health Ministries, care providers and networks, other government departments (provincially and federally), standards organizations, representatives of special communities, and *Infoway*. Each has a role to play, but cooperation and coordination is required in order to achieve optimal deployment and management of telehealth. *Infoway's* Telehealth vision and investment strategy will support the required cooperation and coordination.

2.0 Health Care 2003 – A Snapshot of Drug Prescription Management Robyn Tamblyn, McGill University. Montreal QC

A brief overview of telehealth in Quebec was provided, before addressing the MOXXII (Medical Office of the 21st Century) project.

Telehealth in Quebec and MUHC.

The "Réseau de télécommunications socio-sanitaire" (RTSS) is the information infrastructure by which health related information applications are being implemented throughout Québec. It is a secure private network based on large bandwidth telecommunications technologies provided through a public-private partnership. It currently links approximately 1600 health institutions. Health and social services share email and use RTSS to transmit images and for videoconferencing (VC). VC started in 2000 in paediatric

cardiology. The Ministry of Health paid for infrastructure for 4 University centres and 32 regional centres, which has now grown to 5 University health centres and over 100 agencies; ~150 sites. Rehabilitation and long-term centres are now joining. All 18 regional health wards have VC capacity.

Policy and technology challenges exist for telehealth in Quebec. Licensure is not an issue internally, but remuneration, the legal framework, sustainable funding, and attitudes require attention. Because the same network is shared across the province interoperability is not an issue (25 sites can be connected simultaneously with bridging). Rather the interoperability challenge occurs when trying to get out of RTSS to link with other agencies (school, daycare). The security aspects of the network limit this and negatively impacts opportunities for progress.

Applications are broad, and products and services keep changing, as does perspectives. For example, Infosante does not consider its 24/7 teletriage program to be telehealth, and the telehealth nature of PACS and MOXXII is questioned. Educational projects tend to develop readily, but clinical applications remain a challenge. McGill University Health Centre (MUHC) is involved in a host of telehealth applications touching most of the Province. These include cardiology, audiology, ENT, speech-language pathology, radiology, CHIN, televisitation, neurology, psychiatry, and respiratory medicine. In the future, additional applications will include remote sign language, palliative care, psychiatry, home monitoring, emergency-trauma, audiology, obstetrics, fertility clinics; nephrology, radiology, ultrasound, dermatology, genetics, pathology, and pharmacy.

MOXXII (Medical Office of the 21st Century) project

People care about drugs. Drug costs are the third largest, and fastest growing, sector in healthcare (\$102B in 2001), and control over this seems out of reach. Optimizing prescription drug use will help, but an example of current practice (based on real-life events) illustrates the fragmented way our health system works, and the challenges faced in correcting it.

The following scenario was presented. An older person suffers from several chronic disorders (diabetes, heart problems, and arthritis). She develops a urinary tract infection and attends the local clinic attached to the hospital where she is prescribed Cipro. Shortly thereafter she sees her cardiologist, who renews her medications (Digoxin, Lasix, slow potassium, Warfarin, and Glyburide), and a rheumatologist (after a 14 month wait) who prescribes Vioxx. She fills these prescriptions at a nearby pharmacy, and when she gets home finds they won't all fit in her handbag – so she takes one old medication container and puts a mixture of all her meds in it. No one has caught the drug-drug interactions between Cipro, Warfarin, and Glyburide that increases the risk of bleeding. As a consequence, two or three days later she suffers a severe headache and weakness on her left side. When at the emergency room is diagnosed with a haemorrhagic stroke with seizures. The emergency physician, concerned with the number of drugs in her container, checks with the pharmacist who confirms she is only on Vioxx. She is admitted and seen by neurologist who prescribes Dilantin to control the seizures. On her way home the next day she fills the prescription, but it is hard to read and the pharmacist dispenses twice the desired daily dose. Later at home she becomes dizzy, falls down some steps and fractures her hip, and is taken to the hospital. And her dog – her only companion – had to go to a foster home!

Research shows that almost half (47%) of all drug related hospital admissions are preventable, and are related to under or over use (10%), suboptimal drug management (17%), prescribing errors (18%), or drug and alcohol interactions (3%). Only 21% of the population has one prescribing physician and the risk of unrecognized drug-drug interactions increases with the number of physicians involved in a patients care (100% risk at 9 physicians). Similarly, 59% of the population uses only one pharmacy, but the risk increases as the number of pharmacies involved increases. Transcription errors account for ~ 13% of errors, about 1.6% (~2 in 100) are serious. Handwritten prescriptions will be banned throughout the US by 2007.

Four challenges were identified: more efficient communication between physicians and pharmacists, reduction of inappropriate prescribing and prescribing errors, enhanced compliance with treatment, and improved matching between need and therapy.

To address communication the use of Smart Cards or of a PharmaNet was considered, but in 1995 it was recognized that Quebec already had a large drug database used for claims adjudication, and therefore knowledge of what was dispensed was available. After negotiations, it was agreed to trial linking of physicians on-line with complete information on current medications for these patients. This application provided physicians with comprehensive information about drugs they prescribed, and about drugs other doctors prescribed. In addition coded drug information alerted the physician when there was a drug-disease or drug-drug problem (55 alerts and recommendations were built).

Research from this trial of 110 physicians after 1-year follow-up (15,000 elderly patients) showed that the system reduced inappropriate prescriptions by 20%. It was also learnt that in multi-practice and real-life settings there was a need for a portable solution, for computer training (1/3 had never used a computer before), and reliable equipment (80% of computers had problems at the outset). In addition, physicians needed a prescribing system for all patients (e.g. the privately insured, not just the elderly), needed to know the indication for the prescription, when any prescription was stopped, and an interactive alert right at the point the prescription is written. Although effective, it was concluded this first trial approach was expensive to support, and a different model was desirable. This gave rise to MOXXII – a redesigned, mobile, integrated system for prescription drug management.

A portable PDA-based system was developed. Physicians write prescriptions or stop orders on it, they are sent via a wireless network to the MOXXII server and database. When the patient goes to the pharmacy, they take a unique code that provides the pharmacy with access to the prescription – this is completely an end-to-end computer system (no human interference). The dataflow took two years to work out with the pharmacies, and still includes connections to insurers. Effectively a micro-pharmanet has been created.

To minimize data entry, the physicians database was pre-populated (with patient consent) with data about everybody they have ever seen, and every prescription they had written, by transferring data from the Provinces one billing agent (RAMQ - medical insurance provider for the province). This real-time movement of data out of their system required a policy and legislative change for RAMQ who liked the concept but realized it changed their role in the healthcare system (they were also legislated to provide data for research.) The MOXXII system also pulls information from community-based pharmacies, reconciles it for those insured, and lists it in a user friendly way. The software now provides a menu for appropriate dose selection, shows the drug supply available, colour codes alerts, simplifies stop or change-order requests, and provides information about ER visits and

hospitalization. This allows value-add benefits such as identifying and resolving compliance issues with patients, providing automated refill reminders, identifying problem prescriptions, enhancing team management through e-referrals and shared care models, and use of CPG's to facilitate evidence-based decision support.

MOXXII is opening new opportunities for optimizing prescription drug use. The College of Physicians and Surgeons of Quebec are strongly supportive of MOXXII as a clinical tool. Also, McGill has created a spin off company to commercialize the base system, which has potential for application in other provinces and for larger pharmacies.

3.0 EHR to PHR: The Yin and Yang of Personal Health Data

Verle Harrop, Group Leader for e-Health, National Research Council (NRC).
Saint John NB

The NRC IIT (Institute for Information Technology) e-Business e-Health, located in Saint John New Brunswick, is researching and developing a Personal Health Record (PHR). The PHR is a tool enabling Canadians to proactively engage with their personal health data. It is designed to support prevention, health & wellness, as well as chronic disease management, and to a limited degree acute intervention.

The NRC recently considered its role in e-health and development of a national agenda. To assist in this process, healthcare needs were visualized as a continuum that extends from 'acute interventions' to 'disease management' to 'prevention' to 'wellness'. Within New Brunswick estimates suggest around \$1.8B is spent on acute interventions and disease management, but only ~\$250K on prevention and wellness. This disparity was considered uniform across the country, emphasizing the need for greater effort towards the right of the equation, including the means to collect longitudinal data and information generated by communities and individuals (viewed as untapped resources).

Community based support groups and networks have been identified as a phenomenal resource to support right-hand activities. The Journal of the American Medical Association recently predicted that 88M people will be seeking health information and services online by 2005 - not just information, but services. Indeed, we already spend \$14B per year in out of pocket expenses related to healthcare, supporting the notion of Hertzlinger who, in 1997, stated we were headed towards market-driven healthcare where consumers drive the health care industry through their need for control, self-mastery, and convenience. How much might we be willing to spend to support disease management, prevention, and wellness?

Our changing cultural norms are impacting the role of the enabled individual. We are evolving towards 'something' and there is a need to understand what it is and plot a path to it. In so doing, we need to think about the e-tools and e-infrastructure required to support individuals, communities, and corporations in pursuing wellness and disease prevention. NRC undertook to build an e-health R&D capacity and facilitate collaboration amongst partners in seeking a PHR solution. Initial partners were New Brunswick's Universities, Department of Health and Welfare, Office of e-Health (OeH), Regional Health Authorities (RHA's), Industry, and Canada's Medical and Health Informatics community. Future partners will include other agencies and institutions across Canada, the US, and abroad. It is essential that we work together to create a vision that accommodates all of these players.

To facilitate this collaboration, NRC established the IIT e-Business e-Health centre in New Brunswick.

NRC considers EMR and PHR to be distinct, and therefore that there is a need to provide Canadians with both. One argument in favour of an EPR is the fact that not every Canadian has a family practitioner. About 8,500 out of every 100K Canadians are on a registry waiting for a primary care physician, and walk in clinics are becoming follow-up clinics. In Saint John, New Brunswick ~28% of people in the downtown core live below the poverty level, and many have serious health care issues and are without a physician. An EPR might be the only health related record such people have, since the EMR (Electronic Medical Record) is considered the purview of health information systems, involving primary care practitioners, hospitals, University Health Centres, and pharmacies. In contrast, the PHR (Personal Health Record) is everything collected by individuals and communities, collecting data from all over, and it is owned and controlled by the individual (avoiding many legal and privacy issues). But where can this data go – what tool or e-infrastructure do we have to support a person's engagement in the quest for wellness. A PHR is the solution. Ironically, a pet PHR (called Healthminder) already exists, but no such equivalent exists for people.

Two primary options exist for PHR models – proprietary or open access models. In November 2000, 30 active PHR's could be identified worldwide. Since that time 18 have gone, and 5 have been acquired by GE or WebMD. NRC has determined to develop Canada's PHR as open source, seeing a huge penetration of open source into the health care delivery system in the next 5 to 7 years. In addition, open source appeals to our Canadian sense of what is right, and leverages our collective intelligence and expertise.

If a PHR is created, will it be used? In order to sustain behavioural change individuals must be engaged with their personal health data and have community support. Providing a person with graphically displayed blood sugar levels over a week, concomitantly with tracking of their exercise program alongside can help this engagement process. Giving individuals the data displayed in a simple fashion is compelling, and encourages them to modify their behaviour accordingly. Community support will also help – sometimes referred to as 'the Tim Hortons factor'. Already grocery stores and pharmacy chains are offering cholesterol management clinics and diabetic education clinics, all of which would benefit from documentation of results in a PHR. But research shows that it is very hard to get people to focus their time, effort, and money onto the right hand side of the equation – towards prevention and wellness. Incentives should be sought to encourage this, and no route should be discarded. Providing tax breaks for people who actively use the PHR and its content might be a stimulus. Developing policy to ensure its adoption in 'big box shops' (health booths or kiosks that provide health-risk calculators), and providing air-miles might be others.

Based upon its research and consultations, NRC sees a clear need for a PHR, and its vision has become 'Go Big or Go Home'. Workshops portray the characteristics and architecture of the Canadian PHR as being owned and controlled by the individual, free of charge through the NRC website (allowing global access), containing a core data set that follows a health model (rather than a disease model). Security will be high, the sharing of data will be highly customizable, the individual will determine who has access to what data, and access will be audited. The PHR will always have some educational component and security.

NRC is making progress on the PHR through working in an inclusive, transparent, and consensus driven manner. Much work remains, and many issues must be addressed, including architecture, governance, legal and ethical issues, privacy, security and trust issues, standards and versioning protocols, and business models. In 2004, NRC and its partners will research and develop the PHR. The citizen owned and controlled PHR is considered a natural and necessary complement to the EMR, integral to universal health care, and an essential vehicle for affecting universal healthcare delivery and reform. This open source, web-based tool will be available to all Canadians on a voluntary basis, and will enable Canadians to proactively engage in personal health and wellness, prevention, chronic disease management, and acute interventions.

Section IV: Final Session - Group Discussion

Group discussion in the final Workshop session focused on key lessons arising from the funded projects, as well as required action steps to move the telehealth agenda forward.

I. Key Lessons

Based on the Workshop presentations, the participants outlined the following key lessons for the telehealth community, as well as detailed required steps to move the telehealth e-health agenda forward. The key messages were in four categories.

1. Required characteristics of applications:

- citizen centred
- sustainable
- addresses patient safety
- convergence of e-learning and e-health
- partnerships and collaboration
- policy alignment
- identified need
- feasibility has been demonstrated.

2. Operational and organizational:

- confirmed readiness (deployment and implementation)
- strong project and change management
- business and communication plans
- training and education
- academic training (graduate/undergraduate)
- physicians, nurses, etc.

3. Research and Evaluation:

- Research is required around both innovations and operations as e-health is still immature. Telehealth can help modernize the health system. Industry Canada is working on the innovation model, and has noted that it takes about 18 years for the idea/concept and experiment to move from inception to deployment. e-Health is still in its infancy stage and may take 50 years to reach its mature stage.
- Research specific to how to bridge the gap between innovation and operation is required.
- Researchers and grass-root stakeholders need to develop communication strategies.
- Indicators of success are needed (outcomes and measures).
- Consistent terminology and definitions (e.g. e-health glossary).
- Dissemination of best practices and lessons learned is critical.

4. Funding:

- Funding is required for both e-health innovation (R&D) and implementation activities. Funding at all stages is required (early stage; proof of concept; early deployment; implementation)
- Multiple funding partners will be required. Examples of funding sources include: SSHRC; NSERC; CIHR; EU 6th framework; CANARIE (CANET4); MIT (business plan competition). Innovative ways of using other people's money is required.

II. Action for moving forward

In order to move the telehealth e-health agenda forward, nine areas for focus were identified.

1. Knowledge management, translation and dissemination

- National telehealth community requires ready access to best practices and shared lessons learned. This would require easy reference and proper indexing tools. Perhaps CST, CANARIE, OHIH, and *Infoway* could collaborate on such an activity.
- Share policies, procedures and guidelines from working systems across the country.

2. E-integration

- For certain jurisdictions i.e. rural / remote, northern, align e-health with other sectors e.g. e-learning, e-business (there are grey areas where sectors converge).
- Align e-health, EHR, and telehealth initiatives.

3. Policies

- Policy and system alignment where telehealth activities need to link closely to the primary health care reform so that PHC providers understand the benefits of ICT. This may include gelling of information to planners.
- Do not recreate policies but integrate e-health policies into existing policies. New e-health policies are exceptions rather than rule. Further amend policies that discourage, that preclude, or disadvantage e-health.
- Harmonize policies across the country by sharing policies, procedures and guidelines from working systems. Initial funding may be required as this involves a set of processes.
- Need to inform deputy ministers of front line health care issues.
- Need for policy, system, and management alignment.

4. System and ICT alignment

- Support and training for telehealth use, there exists a lack of digital literacy among physicians.
- Integrate telehealth into existing health system using technologies to ensure the system is sustainable.
- How do we integrate the health system, home and hospital to follow them through the continuum of care?
- Link more closely to Primary Health Reform movement; including gelling information for planners (If EHR was fully implemented then telehealth might be implemented faster in primary health care).
- Implicitly wellness and rationing may have to be applied to resolve the conflicting goals of modernization and sustainability.
- There should be incentives developed for all national strategies, e.g. focused areas (e-childcare, e-homecare).

5. Social Marketing / Mainstreaming

- Get the message out so as to mainstream (i.e. find a group interested in promoting the “innovation” info practices to the public). Feasibility for the projects presented has been demonstrated and promoting e-health could be done by individuals already involved in telehealth projects.

- If telehealth is to be consumer driven, marketing is required. Sell/market telehealth to the public by answering these questions: What is telehealth? How is telehealth going to change their lives? What is it going to do for them?
- CST with support of federal government might pursue some social marketing activity to promote the use of e-health.
- Publicize completed activities by showcasing them to the press.
- Use communication channels to promote awareness of research with grass roots people.
- Partnerships and collaboration required for success.
- Develop a national strategy for home telehealth so we can move specific avenues forward.
- Develop a business model for all telehealth applications prior to implementation.

6. Human Interaction and change management

- Harmonize different cultures towards a common goal (i.e. collaboration).
- Ongoing reviews of the change management process.
- Opportunities for development of human telehealth networks.
- Think about telehealth for resolving and planning “health” human resources.

7. Business and Industry partnerships and collaboration

- Private/business partners have a different perspective of telehealth outcomes from academia. The business goal is to market/commercialize the telehealth application versus the academic goal of creating telehealth intellectual property.
- Government should support training health care professionals regarding e-health product purchases.
- R&D needs to do more with the business part.

8. Funding

- Multiple sources (i.e. continuum of funding depending on stage of innovation).
- Although recent funding announcements promises opportunity for rural, remote, aboriginal and official language minority communities, there is a need for additional funding to protect current investments as they move towards sustainability.
- Fund innovation and practice. Support full spectrum from R&D to deployment.
- Find ways of using “other people’s” money (i.e. non-government sources)
- A gap analysis of funding of telehealth projects is required.
- Develop a strategy for new incentives/funding.

9. Research and Evaluation

- Evaluation should be based on project objectives
- Link innovation and practice agenda.
- All projects should have as its goal the modernization of the health system to ensure sustainability.
- Normalize the cost in those projects where the goal was societal e.g. telemedicine implemented where there was no service, perhaps it can’t be costed. If these projects were rolled out to university-educated people in urban settings, might have a different outcome. It is important to recognize practical and academic views regarding outcomes.
- Publicize completed activities by showcasing them to the press.



Section V: Conclusion

CANARIE is recognized as an important vehicle with which to position Canada as the global leader in advanced networking and innovation in telehealth. Supporting the sharing and exchange of information through this Workshop, and disseminating an associated Report, is one means by which CANARIE demonstrates return on investment for the Projects they have sponsored. This Report outlines what has been accomplished through CANARIE's Phase 3 e-Health and SIP projects, and more importantly provides a sustainable product that shares advice, knowledge, and lessons learned. The wisdom gained through the conception, design, implementation, evaluation, product development, and marketing of these activities, brings extensive value to future e-health explorers striving to apply advanced technologies, mainstream e-health, and/or develop market and commercialization opportunities.

Appendices

Appendix 1: Workshop Program

Appendix 2: Workshop Participants

Appendix 3: Presentations

NB. Appendices are available for download here:

<http://www.canarie.ca/conferences/telehealth/index.html>