

**National Telehealth Outcome Indicators  
Project [NTOIP]**

***Project Information  
Document***

***and***

***A Synthesis of Telehealth  
Outcomes Literature***

**May 2003**



Atlantic Health Sciences Corporation  
Corporation des sciences de la santé de l'Atlantique



**Funded in part by CANARIE Inc. and The Richard Ivey Foundation**



# ***National Telehealth Outcome Indicators Project [NTOIP]***

**‘A Canadian Consensus Approach to Identification  
and Definition of Outcome Indicators for Evaluation of  
Telehealth’**

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## Reader Information

HTU Domain	e-Health Impact and Outcomes
AHSC Domain	Research Services
Keywords	Telehealth, e-Health, Outcomes, Health Services Research, Outcome Indicators, Definitions
Document Type	Information Document
Document Purpose	Contract Deliverable
HTU Ref	03-04
Title	<i>National Telehealth Outcome Indicators Project [NTOIP] - Project Information Document and a Synthesis of Telehealth Outcomes Literature</i>
Abbreviated Title	NTOIP Information Document
Author(s)	Dr. Richard E Scott, Dr. G Frank McCarthy, Dr. Penny A Jennett, Tara Perverseff, MA, Dr. Maria F Palacios, Bonnie Rush, MSc
Publication Date	May 2003
Recommended Citation	Scott RE, McCarthy GF, Jennett PA, Perverseff T, Palacios M, Rush B. <i>National Telehealth Outcome Indicators Project [NTOIP] - Project Information Document and a Synthesis of Telehealth Outcomes Literature</i> . Health Telematics Unit, University of Calgary. March 2003.
Target Audience	Broad telehealth / e-health community
Dissemination	NTOIP Website : <a href="http://www.ucalgary.ca/ntoip">www.ucalgary.ca/ntoip</a>
Description	Provides a description of the Canadian National Telehealth Outcomes Indicator Project, a rationale for the need to identify and define consistent outcome indicators, a synthesis of the telehealth outcomes literature, and a Telehealth Outcomes Development (TOD) model to guide the process. Appendices provide additional information regarding several international health outcomes projects, and potential tools.
Funding Sources	CANARIE Inc., Richard Ivey Foundation, plus in-kind support from the Health Telematics Unit and Atlantic Health Sciences Corporation.
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## Executive Summary

Considerable local, national, and international activity has taken place in recent time to identify indicators of health system performance. This has been driven by the growing call for accountability by the healthcare sector – a sector with a voracious appetite for money. At the same time, telehealth has been gaining prominence as one possible solution to the need to deliver healthcare more equitably to urban and rural-remote communities. Yet telehealth has not been adopted at the rate anticipated by some. Research has shown some of this to be related to human issues such as a lack of readiness and change management, but another reason lies in the cost and lack of clear evidence of ‘value’ for telehealth.

Researchers have not provided senior healthcare administrators and policy makers with the high quality, consistent, and irrefutable scientific evidence required to make critical decisions about spending already scarce healthcare dollars on telehealth. Time and again it has been shown that the quality of telehealth research needs to be enhanced. Further, a striking aspect of the growing telehealth literature is the lack of consistency between studies in terms of evaluation frameworks applied, outcome indicators and measures available and adopted, and tools available and applied.

The focus of this project is on the issue of outcome indicators. At this time we have no agreement on which quantitative or qualitative measures (i.e. outcome indicators) are appropriate and most valuable when evaluating telehealth applications. Worse still, there is no accepted definition for any of those measures that have been used to this point in time. As a result, there is tremendous uncertainty as to the general applicability of evaluation data, and direct comparison of one evaluation with another is rendered futile or even misleading.

To address this issue the project ‘A Canadian Consensus Approach to Identification and Definition of Outcome Indicators for Evaluation of Telehealth’ was conceived. This report or ‘Information Document’ represents the culmination of a systematic review of the telehealth literature to determine what outcome indicators have been used and what definitions may exist. It is intended to be a tool from which the remainder of the project will unfold.

The ‘Information Document’ clearly demonstrates that a myriad of telehealth “outcome indicators” have been measured in some manner, but that these indicators have typically been those for which data could be easily generated, rather than indicators that represented a true and meaningful outcome. It also shows that very few definitions exist, and the same measures may not have been used consistently between studies. If telehealth outcome indicators are to be useful they must be chosen according to strict criteria rather than in the prevailing *ad hoc* manner. Further, for them to be informative, they must accurately reflect the fundamental elements of the system being measured. Currently, this is not the case.

Within this volume, the concept of the project is described (Section 1), followed by the rationale for why examining and developing clear outcome indicators is necessary (Section 2). The results of the literature review are presented and discussed, together with a proposed Telehealth Outcomes Development (TOD) model (Section 3). Finally appendices provide information of direct or indirect relevance to the task in hand (Section 4). As the title implies, this report is very much intended to be an ‘Information Document’ that will offer perspective, develop momentum, and provide much of the information needed to move forward.

## **Acknowledgements**

Financial support for this study is gratefully acknowledged, and was provided by CANARIE Inc., through a cost sharing agreement, and the Richard Ivey Foundation, through an open grant. The Atlantic Health Sciences Corporation and the Health Telematics Unit, University of Calgary provided additional 'in-kind' support.

The investigators gratefully acknowledge the support provided by Diane Lorenzetti, Research Librarian, in the Centre for Health and Policy Studies, University of Calgary, for her assistance in refining, defining, and performing the literature search.

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## Acronyms

ADL	Activities of Daily Living
ANZTC	Australian New Zealand Telehealth Committee
ATDM	Automated Telephone Disease Management
ATM	Asynchronous Transfer Mode
CASPE	Clinical Accountability, Service Planning and Evaluation
CBA	Cost Benefit Analysis
CC	Cost Comparison
CEA	Cost Effectiveness Analysis
CEO	Chief Executive Officer
CIHI	Canadian Institute for Health Information
CIO	Chief Information Officer
CIPP	Context-Input-Process-Product
CMA	Cost Minimisation Analysis
COACH	Canadian Organisation for Advancement of Computers in Health
CST	Canadian Society of Telehealth
CUA	Cost Utility Analysis
DDN/DDS	Dedicated Digital Network/Digital Data Service
DRG	Diagnosis Related Group
EC	European Community
ECHI	European Community Health Indicators
EHR	Electronic Health Record
EU	European Union
FTF	Face to Face
FPT	Federal / Provincial / Territorial
GP	General Physician
HSURC	Health Services Utilisation Research Commission

IADL	Instrumental Activities of Daily Living
ICD-9	International Classification of Disease version 9
ICD-10	International Classification of Disease version 10
IOM	Institute of Medicine
ISDN	Integrated Service Digital Network
ISO	International Standards Organisation
Kbps	Kilobits per second
KUUC	Knowledge Utilization - Utilisation des connaissances
LAN	Local Area Network
MDC	Major Diagnostic Category
NCCLS	National Committee on Clinical Laboratory Standards
NHMBWG	National Health Ministers' Benchmarking Working Group
NHOP	National Hospital Outcomes Program
NLM	National Library of Medicine
OECD	Organisation for Economic Co-Operation and Development
OHIH	Office of Health and the Information Highway
PIRC	Performance Indicators Reporting Committee
POTS	Plain Old Telephone Service
RCN	Remote Consultative Network
SF-36	Medical Outcomes Trust Short-Form 36
StatsCan	Statistics Canada
TMPQ	Telemedicine Perception Questionnaire
WAN	Wide Area Network

## SECTION 1

### *Project Description*

**“At this time there is no regional, provincial, or national agreement on which quantitative or qualitative measures (i.e. outcome indicators) are appropriate and most valuable when evaluating telehealth applications.**

**Further, there is no accepted definition for any of those measures that have been used to this point in time.”**

**(Scott, McCarthy, Jennett; 2001)**

# 1 Project Overview

## 1.1 Rationale

CEO's of hospital corporations, senior bureaucrats, and Ministers of Health are each faced with the need to make major decisions regarding the allocation of already scarce healthcare resources. How should telehealth 'solutions' fit into their deliberations? Where is the research that has accumulated essential data using key outcome indicators - consistently measured in all of the telehealth options they may wish to compare? Simply put – it does not exist.

This 'Information Document' clearly demonstrates that a myriad of telehealth "outcome indicators" have been measured in some manner, but these indicators have typically been those for which data could be easily generated, rather than indicators that represent a true and meaningful outcome. If telehealth outcome indicators are to be useful, either at a local, national or, international level, they must be chosen according to strict criteria rather than in the prevailing *ad hoc* manner. Further, for them to be informative, they must accurately reflect the fundamental elements of the system being measured. Currently, this is not the case.

At this time there is no regional, provincial, or national agreement on which quantitative or qualitative measures (i.e. outcome indicators) are appropriate and most valuable when evaluating telehealth applications. Further, there is no accepted definition for any of those measures that have been used to this point in time. As a result, there is tremendous uncertainty as to the general applicability of evaluation data, and direct comparison of one evaluation with another is rendered futile or even misleading. There is, therefore, an urgent need for standardisation of telehealth outcome indicators. It can be argued that as a developing field, it was necessary to first build a body of experience and knowledge. Although valid, the time is long overdue for a concerted effort by those in the field to develop, and consistently apply, telehealth outcome indicators.

The results of this and similar endeavours will be invaluable for advancing telehealth / e-health domestically and globally, encouraging continued investment in 'proven' solutions, and informing e-health policy.

## 1.2 Purpose

The purpose of the project is to overcome one barrier to the broad adoption of telehealth; that is, the lack of uniformly defined and measured outcome indicators to adequately demonstrate and compare the value of diverse telehealth applications. This project addresses this fundamental barrier through a national consensus building process for adopting outcome measures in four dimensions of telehealth evaluation - quality, cost, access, and acceptability.

As a result of this activity, several advantages are anticipated:

- Systematic identification of telehealth outcome indicators will be promoted
- Areas where indicators are lacking will be identified
- The process of reporting telehealth evaluations will become streamlined
- Comparison between evaluations will become feasible
- Telehealth outcome benchmarks will be established
- In the short to medium term, policy decisions and selection of appropriate telehealth solutions will become informed.

### **1.3 Objectives**

The objectives of this project are to *identify* and *define* nationally accepted sets of outcome indicators that can be universally accepted and used by the broader telehealth community when comparing or performing evaluations of telehealth applications. Adoption of common telehealth outcomes nationally will help ensure that telehealth evaluations are performed with some uniformity across all services and jurisdictions. This will facilitate informed policy debate and discussion about telehealth and its applications.

The term 'broader telehealth community' is used in reference to the anticipated user group that could benefit from having such specific guidelines for telehealth outcome indicators. This 'user group' is very broad, and includes governments, healthcare organisations, industry, funding agencies, professional groups and societies, academics, and the public.

### **1.4 Intent**

It should be noted that the Outcomes Guidelines developed through this project are intended to become sets of agreed upon principles, not regulations. This accepts and respects the need for growth, adaptation, and program specific indicators in the future. Guidance on specific issues could be addressed in accompanying commentaries capable of easy and timely revision while leaving the basic Guidelines intact.

Similarly, these Guidelines are intended to focus on telehealth / e-health, yet be complementary to, and indeed build upon, other similar initiatives outside of telehealth / e-health. Thus, existing domestic programs for the collection and analysis of health indicators must be examined and, where applicable, existing indicators (and definitions) identified for inclusion in the developing telehealth Outcomes Guidelines. At the same time, such existing programs cannot be expected to address the needs of telehealth evaluation, and therefore this project will augment and/or supplement these currently used or developing programs.

Finally, even with consensus guidelines in place, individual jurisdictions can be expected to apply them differently. This project will provide a 'smorgasbord' of indicators from which individual jurisdictions can select. This will develop commonality of evaluation, yet also permit flexibility for jurisdictions to develop or focus on alternate indicators of importance to their own setting. It is also anticipated that this will become a self-perpetuating activity, with jurisdictions contributing proposed indicators for inclusion as new issues emerge and additional data become available.

### **1.5 Evaluation Models and Outcome Indicators**

A number of 'models' for telehealth evaluation have been documented in the literature. Of these, four are known to be used within Canada and are noted below. We believe it is possible to identify common outcome indicators that can be used within any given evaluation model. This retains the value of identifying and defining common outcome indicators yet also retains the desired flexibility in applying specific models to specific settings.

**Institute of Medicine.** In response to a request by the National Library of Medicine (NLM) for a "broad framework for evaluating clinical telemedicine", the Institute of Medicine developed a report over a 3 year period of consultation and deliberation that was published in 1996 (Field, 1996). One review noted that this document represented "the

most comprehensive discussion of clinical telehealth evaluation developed to date” (McCarthy *et al*, 2000). Although now old, it remains of value, and was the first comprehensively described framework designed solely with telehealth in mind. It encompasses many of the key evaluation features advanced in the literature; reflects the contributions of many of the (then) leading proponents of clinical telehealth; is broad in scope (although failing to address application-specific provisional and outcome measures and criteria); and develops broadly relevant evaluation questions concerning the issues of quality, accessibility, cost and acceptability of clinical telehealth.

**Balanced Score Card.** This is an established approach to evaluating the performance of organisations, and gained popularity in Canadian hospitals during the 1990’s. A number of organisations are now using this approach in relation to telehealth. A Balanced Scorecard approach provides a framework to describe and align strategy across an organisation within four quadrants. The quadrants described in this particular Balanced Score-Card model are: Patient / Provider Satisfaction; System Integration / Change; Clinical Utilisation / Outcomes; and Financial (Roston *et al.*, 2002). Overall, this model provides a methodology for aligning and communicating goals with those whose performance is ultimately responsible for achieving them. This approach typically assesses past performance using a combination of leading and lagging indicators across the four quadrants. Performance as measured by specified indicators is evaluated, and is used to implement and manage organisational strategy and change. In this way the model supports successful implementation of technology into the existing complex organisational structure.

**Modified CIPP / Donabedian.** The original “gold standard” framework for evaluation of health services was developed by Donabedian beginning in the 1970’s and 1980’s (Donabedian, 1988). The framework conceptualises any health service as having three components *structure, process and outcomes*. **Structure** (also called inputs) refers to facilities, staff, materials, financial resources and baseline client characteristics (such as socio-demographics). The **process** phase (also called outputs) refers to all aspects of service delivery including access, triage, assessment, treatment, follow-up, referral and related activities. In the **outcome** phase the effects or impacts of services are considered, including (but not limited to) the classic four outcome areas, *improved clinical condition, functioning, quality of life, and client satisfaction*. In principle, all program objectives can be classified according to these three phases. The Donabedian framework was expanded by Tansella and Thornicroft (1998) to include another useful dimension – the service level.

More recently Hebert (2001) proposed a novel telehealth evaluation framework that expands upon Donabedian’s original framework, and explicitly separates the structural and outcome variables into individual and organizational categories. Similar to the goal for adoption of any framework, the advantage lies in examining all similar studies using the same framework to extract commonalities and differences. This modified Donabedian model is intended to begin development of a body of knowledge around telehealth evaluation, and to identify influential relationships among the success variables defined for telehealth.

**CHIPP.** In recent years, the federal government has invested many millions of dollars in health infostructure in Canada through various initiatives. The Canadian Health Infostructure Partnerships Program (CHIPP), launched in 2000, is contributing \$80 million to support the implementation of innovative telehealth and electronic health record (EHR) applications in health service delivery across Canada. It is expected that this investment will accelerate technology-enabled healthcare renewal throughout the country and improve the accessibility and quality of healthcare for Canadians, while increasing efficiency and protecting the long-term viability of the health system. To help determine the extent to which these expectations have succeeded, every CHIPP-funded project and CHIPP itself will be evaluated.

The CHIPP Evaluation framework advances beyond the IOM model, and adapts it to CHIPP's broader range of goals and objectives, e.g. encompassing EHR (Electronic Health Records) as well as telehealth, and acknowledging the context of a publicly administered, publicly-funded health care system. It's development was based on a literature review and policy environment scan, and lessons learned from similar funding programs. It was then vetted through an advisory committee. The framework was part of the CHIPP Request for Proposals, and all CHIPP funded projects were to adopt and adapt the framework to meet their specific project needs. Once all the projects were up and running, an analysis was done that included frequencies of indicators used, and commonalities and differences identified. It is considered to represent a Canadian framework, provide a basis for short-medium-long term analysis, and offer consistency of general indicators. It will allow each project to prove value and impact. Finally, for Health Canada, it will offer strategic policy and research development opportunities (Chatterton and Hanson, 2002).

## **1.6 Context**

Although specific telehealth / e-health applications have been 'evaluated', the literature repeatedly shows the evaluations have typically been of poor scientific quality, limited in scope, and often technical in nature (Jennett *et al.*, 2003; Hailey, 2002). No formal, structured process has yet been undertaken to examine which outcome indicators are appropriate for broad evaluation of telehealth activities, nor has there been any in depth effort to rigorously define any such indicators. By providing tools that permit clear demonstration of value, this project will identify - indeed set - best practices, allowing 'proven' telehealth applications to be confidently implemented and justly showcased.

## **1.7 Limitations**

The goal of this project is huge in scope, and it will not be achieved by one study alone. It is proposed that this will be the foundation for an increased recognition of the importance of the issue and goal, and will lend support, within each individual's sphere of influence, to the stated purpose.

Compromise will be necessary, since not all aspects of telehealth can be addressed immediately. It may well be necessary to focus thoughts and efforts in limited directions (e.g. clinical vs. administrative applications) and within groupings (e.g. teledermatology vs home telehealth / telehomecare). Each of these are "different" areas of telehealth application, but their evaluation should encompass common needs, and therefore at least some common outcome indicators.

## **2. Project Framework**

The project framework provides a structured and systematic process, elements of which have been proven in other settings, through which to achieve success and national agreement on suitable outcome indicators for evaluation of telehealth applications. It will answer the primary research questions:

1. Which specific outcome indicators are most suitable for evaluation of telehealth applications, and
2. How must identified outcome indicators be described to provide unequivocal definition, acceptance, and adoption by the broader telehealth community?

In determining an approach to the study, existing examples were sought that could be incorporated and ensure success. First, the IOM (Institute of Medicine) model was chosen to provide the baseline from which to identify outcome themes for the present study (quality, access, acceptability, and cost). Second, the NCCLS (National Committee on Clinical Laboratory Standards) model from the USA was chosen as the base for a suitable process to permit national consensus to be developed on identifying 'candidate outcome indicators'. Third, the CASPE (Clinical Accountability, Service Planning and Evaluation) model from the UK was chosen to provide the principles for rigorous definition of identified candidate outcome indicators. Each of these is described below.

## ***2.1 Institute of Medicine (IOM) Model***

In 1996 a book was published that identified managerial, technical, policy, legal, and human factors that must be taken into account when evaluating a 'telemedicine' program (Field, 1996). The book had its origins in a 3-year deliberation by an IOM committee that reviewed previous efforts to establish evaluation frameworks, and reports from several completed studies of image transmission, consulting from remote locations, and other telemedicine programs. The committee also examined basic elements of an evaluation and considered relevant issues of quality, accessibility, acceptability, and cost of health care. While other models have been investigated and applied, and whereas the IOM model is recognised to have deficiencies, it is the first model developed solely with telehealth (telemedicine) in mind, although more recently an evaluation framework around CHIPP has been developed. It was for that reason that the IOM was chosen as the base model for this project, in terms of identifying suitable categories within which to seek telehealth outcome indicators.

## ***2.2 Defining Candidate Outcome Indicators (CASPE)***

A crucial aspect of this project is the desire to clearly define each Candidate Outcome Indicator identified. This type of standardisation is an often ignored, but extremely important, process that is essential for adoption and broad use of outcome indicators. Even something as simple as whether a 'connect' between a hub telehealth site and five spoke sites constitutes one telehealth activity or five – or even six – is unclear, and often used to 'pad' evaluations and reports of telehealth applications. More subtle issues are even less clear, but defining Candidate Outcome Indicators will provide a solid and consistent base to which all members of the broader telehealth community can refer. To achieve this, a process similar to that first described by the CASPE group in the UK for clinical outcome indicators will be used (CASPE 1995). The precise framework used for this project will be devised during the proposed National Telehealth Outcomes Workshop, but the basic CASPE concept (slightly adjusted to reflect telehealth) is outlined in Table 1 (Framework for Defining Candidate Outcome Indicators) below.

## ***2.3 Achieving Consensus (NCCLS)***

Another critical aspect of this project is its fundamental base in consensus. The goal of consensus is the development of one decision that is the best for the whole group. As described earlier, the 'group' that could benefit from having specific guidelines for telehealth outcome indicators is broad, involving governments, health care organisations, industry, funding agencies, professional groups and societies, and academics. The input and comments from this diverse group is essential to the consensus process. Achieving consensus becomes increasingly more difficult in larger groups, yet ironically consensus works better when more people participate.



<b>Table 1. Framework for Defining Candidate Outcome Indicators</b>		
<b>#</b>	<b>Element</b>	<b>Description</b>
1	Title	Provides a clear but succinct descriptive title of the Outcome Indicator <i>For example: Telehealth connect period; Hospital admission rate; Years of life lost; Number of tele-education events</i>
2	Aim of Intervention	Provides a brief explanation of the purpose of the current intervention that results in the Outcome Indicator <i>For example: Reduce / avoid the risk of .....; Reduce risk of death; Reduce Impact on general well-being</i>
3	Characteristics	Provides a description of characteristics of the Outcome Indicator in 4 domains; <i>for example:</i>
	Specificity	<i>Application specific (Teleradiology); Disease specific; Age specific; Condition specific</i>
	Perspective	<i>Population; clinical; patient; society</i>
	Time Frame	<i>Cross-sectional; Longitudinal</i>
	Outcome Relationship	<i>Proximal or Distal; Direct or Indirect</i>
4	Definition	Provides a precise definition (as specific as possible) so that data collected at different facilities will be consistent
5	Rationale	Describes, in clear but succinct detail, why the Outcome Indicator has value and should be considered for measurement or routine monitoring. The argument must be clear and logical, and – where possible – supported by literature references
6	Potential Uses	Describes if the Outcome Indicator will have only one use, or if it can serve secondary functions also
7	Potential Users	Identified who will most benefit from the information. <i>For example: National, Provincial, or Regional policy makers; Health Care Managers; Clinicians; Patients; Family Members; Public</i>
8	Possible Confounders	Describes what factors may influence the Outcome Indicator <i>For example: Could it be influenced by - diagnostic habit; the health behaviour of patients; co-morbidities, age</i>
9	Data Sources	Identifies if specific measurement is most likely required, or otherwise identifies potential existing sources of data for deriving the indicator Where data are not widely available from existing systems, suggests new and appropriate methods of data collection
10	Data Quality	Describes what limitations may exist with the data
11	Comments	Provides discussion of any perceived pro's and con's of the Outcome Indicator
12	Conclusion	Summarises the information available, and concludes whether or not it is considered a valuable indicator
13	Further Work Required	Describes if some elements require further investigation before the Outcome Indicator can be used or considered for implementation
14	Priority for Implementation	High priority – valuable indicator worthy of recommendation for consistent and immediate implementation Marginal priority – indicator of questionable value that should not be recommended for implementation

For this reason, it is crucial that the consensus process has a clear but simple structure, and that it occurs in such a manner that active and broad participation is encouraged. The web-based strategy used will be an inclusive process that will involve as many people as possible, and encourage participation, allow equal input for critique, develop co-operation, and create a sense of individual responsibility for the final decision.

To achieve this within the proposed project, the basic model used successfully and extensively by the National Committee on Clinical Laboratory Standards (NCCLS) has been adapted. Originally US based, NCCLS is now a globally recognised, voluntary, consensus standards-developing organization that enhances the value of medical testing within the healthcare community through the development and dissemination of standards, guidelines, and best practices. Their voluntary consensus process, developed and used over many years, is achieved through active participation of interested and affected parties drafting, reviewing, and commenting on standards and guidelines. Their model has been adapted to satisfy the needs of this project.

The following principles will be adopted in preparing Outcome Indicator Documents:

- The development and review of documents will be open
- The documents will be revised in response to comments by users
- The final document(s) will be accepted as consensus guidelines

Each Outcome Indicator Document will be subject to two levels of consensus building - "Proposed" and "Tentative." Once revised following the Tentative stage, a document will be deemed "Approved".

**‘Proposed’** An Outcome Indicator Document will undergo the first stage of review as a ‘Proposed’ guideline. During this stage, the document will be distributed widely to encourage a broad and thorough line-by-line review. This review is intended to assure utility and readability, and that the guideline reflects broad consensus. All comments forwarded by contributors to the secretariat will be examined and addressed.

**‘Tentative’** An Outcome Indicator Document will undergo its second stage of review as a ‘Tentative’ guideline. This will be a ‘proposed’ document that has been extensively revised based upon the initial review. In this way contributors will see that their comments have been satisfactorily addressed, demonstrating and supporting attainment of consensus through the process. Again, the document will be distributed widely to encourage a second line-by-line review.

**‘Approved’** An Outcome Indicator Document that has completed the two stages of consensus within the broad telehealth and healthcare community will be termed an ‘Approved’ guideline.

Each iteration of the Outcome Indicator Documents will be distributed to the broader telehealth community and comment invited. A period of about 1 month will be allowed for receipt of comments after distribution as Proposed and Tentative documents. All comments will be examined and addressed. Comments will either result in a change to the document when distributed at the next iterative level, or will be responded to in an appendix to the revised document.

Having proceeded through the above process, the final guidelines will represent a consensus opinion and reflect the substantial agreement by affected, competent, and interested parties throughout the broader telehealth community.

## SECTION 2

### *Developing Outcome Indicators*

**“The overall aim of healthcare outcomes analysis is to *improve healthcare* and to achieve the *optimum benefit* from the *resources available* by assessing the outcomes of different treatments / approaches.**

**Healthcare outcomes analysis is thus a process of *identifying and measuring outcomes* that are *important* to the *relevant target audiences*.”**

***(Rapier, 1996)***

### **3. Outcomes**

This section raises some issues related to outcomes and more importantly provides clear definitions of telehealth / e-health outcome related parameters.

#### **3.1 Defining Outcomes Research**

The following is taken from a report of the Agency for Health Care Policy and Research (Tunis and Stryer, 1998) and provides some historical perspective.

'The terms "outcomes research" and "effectiveness research" have been used to refer to a wide range of studies, and there is no single definition for either that has gained widespread acceptance. As these fields evolved, it appears that "outcomes research" emerged from a new emphasis on measuring a greater variety of impacts on patients and patient care (function, quality of life, satisfaction, readmissions, costs, etc). The term "effectiveness research" was used to emphasise the contrast with efficacy studies, and highlighted the goal of learning how medical interventions affected real patients in "typical" practice settings. Effectiveness studies sought to understand the impact of healthcare on patients with diverse characteristics, rather than highly homogeneous study populations. While the terms may have different initial roots, there does not appear to be much value in distinguishing these activities, and the field is generally referred to as OER (Outcomes and Effectiveness Research).'

**Definition of OER.** 'OER evaluates the impact of healthcare (including discrete interventions such as particular drugs, medical devices, and procedures as well as broader programmatic or system interventions) on the health outcomes of patients and populations. OER may include evaluation of economic impacts linked to health outcomes, such as cost-effectiveness and cost utility. OER emphasises health problem- (or disease-) oriented evaluations of care delivered in general, real-world settings; multidisciplinary teams; and a wide range of outcomes, including mortality, morbidity, functional status, mental well-being, and other aspects of health-related quality of life. OER may entail any in a range of primary data collection methods and secondary (or "synthetic") methods that combine data from primary studies' (Mendelson *et al.*, 1998).

#### **3.2 Whose Perspective?**

The desire to create an evidence-based healthcare system has grown in recent years. Concomitantly, interest has grown in using outcome indicators as the means to demonstrate the link between an intervention and a result or visible effect. A fundamental question arises - 'whose perspective is of most importance'? In other words, whose outcomes should we be measuring?

In our publicly administered, publicly-funded health care system, ultimate consumers (or 'buyers') of healthcare or healthcare information are the tax paying populace. What do these healthcare consumers 'buy' through their tax dollars? They do not directly buy component goods and services (bed days, doctor visits, inpatient drugs, laboratory tests), but they might be considered to 'buy' medical interventions or encounters with the healthcare system for purposes of diagnosis, treatment, or prevention of illness (Bissell, 1996). As in all good business operations it is necessary to ensure the healthcare systems 'processes' run efficiently, but again as in good business operations - in terms of outcomes surely attention should focus on the consumers?

### 3.3 What is an Outcome Indicator?

This represents a remarkably fundamental question, for which a search of the literature has revealed controversy in the health services research arena, and no definition for telehealth / e-health outcome, telehealth / e-health outcome indicator, or other similar descriptor. That proponents of telehealth / e-health have not pursued this more vigorously is surprising (Scott, 2001). It is essential that within the context of this project such definitions be provided and accepted.

Based upon existing health services research literature an '**outcome**', in its plainest sense, is a '**result or visible effect**' (Wilkin *et al.*, 1992; UK Clearing House on Health Outcomes website; Outcome Analysis Workgroup, 1999), and is a relative value (being a measure of change attributable to an intervention or series of interventions). An unclear and complex relationship exists between health, health services, telehealth / e-health, and a myriad of other factors in the social system, therefore an improvement in health need not be solely a result of improved health services.

A '**health outcome**' therefore is the result or visible effect on **health** (healthcare, healthcare related services, public health) of any type of process. This would include not just assessment of healthcare services provided to patients, but it would also include assessment of other socio-economic determinants of health (e.g. housing, social services, employment).

Note that in the definitions below 'e-health' is used exclusively. e-Health is considered an umbrella term; it encompasses both telehealth and telematics related activities, regardless of the communications modality (Internet or otherwise) used to accomplish them.

Based upon the above, the following definitions have been developed.

An **e-health outcome** is defined as:

*The result(s) or visible effect(s) on health, healthcare, or healthcare related services of any type of e-health intervention.*

As such e-health outcomes would encompass not only impact on patients (perhaps the ultimate outcome), but also other areas including education (provider and patient) and administration (including telematics); i.e. any area in which e-health (telehealth) is employed – **CREAM**: **C**linical, **R**esearch, **E**ducation, **A**dministration, or **M**ixed.

It is important to differentiate between the complementary perspectives of measuring what might be termed true outcomes (patient related) versus measuring process outcomes (health system related). In general we are adept at measuring the latter, but are not as adept at measuring – even identifying – other outcomes.

An **e-health outcome indicator** is defined as:

*The parameter it is desired to assess in order to determine if an e-health intervention has had a result or visible effect.*

An outcome indicator should provide information in terms of a longitudinal assessment of a change from one point in time to another.

An **e-health outcome measure** is defined as:

*The specific component or element of an outcome indicator used to quantify (quantitative measure) or gauge (qualitative measure) the result or visible effect of an e-health intervention.*

An **e-health outcome tool** is defined as:

*The specific instrument used to collect quantitative or qualitative data for any single outcome measure.*

Specific tools would include administrative databases, surveys or questionnaires, logs, case report forms (CRF's), key informant interviews, or focus groups.

### **3.4 Proximal and Distal Outcome Indicators and Attribution**

We often are forced to use 'surrogate indicators', in this regard the terms '**proximal**' and '**distal**' are often applied. The question then arises of whether the outcome can be attributed to the intervention. These issues are briefly addressed below.

#### **3.4.1 Proximal and Distal Outcome Indicators**

Proximal outcomes are those results or visible effects that are seen relatively close to the point of intervention along the continuum of the process or procedure being assessed. Changes in proximal outcomes are more likely to be directly related to the telehealth / e-health intervention. Distal outcomes are those results or visible effects that are seen relatively far from the point of intervention along the same continuum. In principle, distal outcomes (e.g. the impact upon a patient's health status or quality of life) often represent the 'true' and desirable outcome and are the best indicators. However, they are difficult to measure, and the further an effect is from the point of intervention the more other confounding factors may influence the outcome. As a result we often strive to identify more proximal and measurable indicators of impact, and use these as surrogate measures.

#### **3.4.2 Attribution**

Did the outcome result directly from the intervention? Research (e.g. randomised clinical trials or RCT's) is the only way to establish a clear link between an intervention and an outcome. However, achieving the desired end-state is the primary aim within healthcare, almost irrespective of how it was caused. Thus, the issue of attribution becomes one of plausibility or likelihood rather than certainty (Shanks and Frater, 1993). One way of enabling a closer link between intervention and outcome is to ensure that the indicators addressed are as relevant as possible to the aims of the user. This also serves to promote the user's view of what the intervention should aim to achieve.

[Adapted from the UK Clearing House on Health Outcomes website].

### **3.5 How Do We Use Outcome Indicators?**

Measuring change in outcome indicators is the means used to assess if an intervention has met predetermined expectations. Such indicators are identified during the planning phase of

a project or program, and success of the intervention is measured against them during the evaluation phase.

### 3.6 How Can We Select Outcome Indicators?

To measure the correct outcome appropriately in any specific situation requires careful consideration. The identified outcome indicator must be appropriate and capable of being readily measured, and a tool must exist or be developed to capture the data in a convenient, unobtrusive manner (particularly in clinical settings). The outcome must, as far as possible, be linked clearly to the intervention concerned, such that the effects are true 'attributable' outcomes and not simply a reflection of a different state of health or some confounder. Any potential mediating or confounding factors must therefore be recognised and noted.

Clearly, identifying what is a suitable outcome indicator is a challenge and not a simple process to do well. In medical applications, the movement towards evidence-based medicine has resulted in the documentation of many clinical outcome indicators, and this process can be emulated when looking for candidate outcome indicators in telehealth.

The International Standards Organisation (ISO) suggests a 'health indicator' must be informative, and sensitive to variations over time and across jurisdictions. The ISO also notes that for health indicators to be useful for monitoring health or health system performance, then *explicit criteria must be applied for choosing and defining them*. Their recommendation is that selection be based on some agreement about what is to be measured, and for what purpose, and that the selection process be informed by a clear, conceptual framework. It is this same conceptual process that is being followed within this project.

The ISO further noted that their general process of working toward a standard health indicators framework "will undoubtedly foster a common language for communication between countries, and ultimately, lead to greater commonalities for indicator development. This could, and should, lead to greater potential for generating internationally comparable health data in the long term, in order to permit consistent reporting, dissemination, and analysis." The same can be said for working toward a common set of telehealth outcome indicators.

#### 3.6.1 Clarifying Desired Outcomes

To aid the process of identifying outcome indicators, a simple outcomes grid can be completed (Table 2) as a prelude. Note: the headings in the top row are for illustrative purposes only, and the interested actors will vary with each telehealth / e-health intervention. Key questions to address with this process include:

- Who are the relevant actors for this telehealth / e-health intervention or package of care?
- What are their outcomes at each stage in the clinical, research, education, or administrative process?
- What are possible associated measures for each outcome?
- What will be done with the data collected?
- Whose outcomes are to be measured and why?
- When should the desired outcomes be measured?

It is only after careful consideration of issues such as these that attention can turn to the choice of specific outcome indicators, and related measures and tools. Going through this process should ensure that only outcomes that are **important** and associated with the **relevant** target audiences are identified and measured.

Table 2. Initial Outcomes Grid to Identify Rationale for Candidate Outcome Indicators				
	<i>Patient / Family</i>	<i>Care Provider(s)</i>	<i>Care Facility</i>	<i>Healthcare System</i>
Reason for interest in outcomes				
Desired Outcomes				
Candidate outcome indicators				
Candidate outcome measures				
Interpreting and using the outcomes data				

[The above was adapted from Long (1995), Long (1996), and the UK Clearing House on Health Outcomes].

### 3.6.2 *Desirable Characteristics of Outcome Indicators*

The desirable characteristics of suitable outcome indicators have been described by several groups, but can be summarised as follows, based upon the IOM model (Field, 1996):

- **Reliable.** Repeated use under identical circumstances by the same or different users must produce the same results;
- **Valid.** It must measure the properties, qualities, or characteristics it is intended to measure;
- **Responsive.** It must detect important differences in outcomes across evaluation groups or time periods;
- **Interpretable.** Users must find the results of its application understandable;
- **Feasible.** Users must accomplish the required activities, collect the necessary information, and analyse the resulting data within available evaluation resources and without imposing excess burdens on those whose cooperation is required for the evaluation;
- **Flexible.** It must be adaptable to a variety of evaluation problems or circumstances, and,
- **Documented.** The protocols for applying and interpreting it must be specified, and evidence of its successful use must summarised or cited.

### 3.6.3 *Reviewing Outcome Measures and Tools*

Review criteria can help determine if an identified and defined outcome measure is suitable for routine use. The following parameters are useful in making this determination.

The following is extracted from the 'UK Clearing House on Health Outcomes' website.

#### **User Centredness**

The user centredness of an outcome measure refers to the extent to which it faithfully captures both the content of user's views and the ways in which those views are expressed by users (their form). User centredness is one point on a spectrum from measurements that take no account of user's perceptions to those that actively encourage users to specify what factors should be recorded and how they should be defined (Dixon and Long, 1995). It is a form of content validity since a measure which aims to capture user's views but does not do



so cannot be described as valid. In selecting an outcome measure to use in clinical practice, clinicians and researchers will wish to identify whether the measure covers domains relevant to the users of their services.

## **Psychometrics**

Any measure must be psychometrically sound. Key psychometric properties include:

- Reliability; that is, does the instrument consistently measure the same thing?
- Responsiveness to change; that is, does the instrument detect changes that are meaningful to both the clinician and the user?
- Validity; that is, does the instrument measure what it purports to? Content and face validity are of greatest importance for measures intended for use within routine practice. These forms of validity question the extent to which the measure captures the views of users and or clinicians and are similar to user centredness.

## **Feasibility**

A central issue of concern is how practical the outcome tools may be for routine use, particularly in clinical settings. Many outcome tools have been developed within research settings where maximising psychometric properties have led to instruments that are too long for routine use. Other factors such as the tools length, its mode of administration, and the ease with which it can be scored and interpreted and fed back within the evaluation / research framework are critical. At the same time, shorter instruments are in general more likely to be less reliable. Thus, a balance is often required between psychometric properties of measures and their tools, and their feasibility for routine use.

## **Utility**

A further review criteria refers to the clinical utility of the information provided by the measure and the settings in which it is appropriate to use the measure. For a measure to be readily adopted, it must have clear stakeholder utility and must provide information that will inform the process of decision making. In other words, it does not simply add to the potential data collection burden.

In addition, the measure must be appropriate for the setting in which the telehealth / e-health application will be used. Many outcome measures have only been validated for use in particular settings or with specific user populations. It is essential that the validity of the measure, in particular its content validity, is checked before it is used in different settings or with a different group of users than those for which the measure was originally designed (Fitzpatrick, 1996).

### **3.6.4 Structured Review of an Outcome Measure**

Table 3 is adapted from the 'UK Clearing House on Health Outcomes' website, and provides criteria with which to conduct a structured review of an outcome measure.

## **3.7 Environmental Scan – What Outcome Activities are There Currently?**

No current activity could be found that addressed outcomes specifically in telehealth. In stark contrast, there is a surprising amount of activity taking place in regard to outcome indicators, largely driven by the recent desire to demonstrate accountability in regard to the cost of healthcare. This activity is not restricted to Canada, and its importance should not be underestimated. ***If these indicators are gaining prominence as 'the' indicators***

<b>Table 3. Criteria and Questions for a Structured Review of an Outcome Measure</b>	
<b>Review Criteria</b>	<b>Key Questions</b>
Purpose	What does the measure aim to do? What does it aim to measure?
Background	Why was this particular measure needed? What was the rationale behind its determination?
Description	Description of the items and subscales in anticipated tools; response format; period of measure; method of administration and scoring; reporting.
User Centredness	Whose perspective does the measure capture? To what extent does this measure capture patient or carer desired outcomes? Is it faithful to the content and form of patient and carer views?
Psychometrics	Is the measure psychometrically sound?
Feasibility	How feasible is the measure – and its tool - to use within routine practice? Consider the length and ease of administration, scoring, interpretation and feedback of the tool.
Utility	Can the information provided by the measure – and its tool - become an integral part of telehealth / e-health decision making? Does it provide extra information not already available?

***against which to assess performance of healthcare and the healthcare system, then there is every reason to believe that telehealth will be held accountable to the same criteria. It becomes prudent to be aware of, and where possible align with, such initiatives.***

Samples of current 'health outcomes' related initiatives have been summarised in Appendix A. A worldwide environmental scan of initiatives relevant to this project located only one related activity conducted by the Australian New Zealand Telehealth Committee (ANZTC). Although now discontinued, the motivation for this activity rings familiar, and was the ...

*"lack of comparable data, as a basis for ongoing monitoring and review and formal evaluation, (that) had been identified as a major impediment to the development of telehealth. Thus, development of common telehealth data definitions and a standard telehealth data set became a key activity within the Committee's Workplan. ... This simple strategy will help ensure that telehealth data is collected uniformly from all services and jurisdictions, facilitating informed policy debate and community discussion in the contemporary healthcare environment" (ANZTC, 1998).*

The process used by ANZTC is simpler than in the current study project, with no clear consensus process and fewer criteria for definition of indicators. Two examples of data elements are provided below as an illustration, and the entire tool is provided for reference in Appendix A, item A6.

#### **Example 1:**

<b>Item</b>	<u>Other sites connected</u>
<b>Definition</b>	Count of all other sites that were involved in the telehealth session while the site was connected to the session.

<b>Context</b>	Telehealth. Indicates the size of a multi-point connection.
<b>Guide for use</b>	Recorded by each telehealth site for all other sites. (Note that there will be some anomalies in the number of sites recorded by each site due to sessions in which some participants drop in and out of the session).
<b>Source</b>	Nil

---

#### Example 2:

<b>Item</b>	<u>Purpose of telehealth session</u>
<b>Definition</b>	The principal purpose or main reason for conducting a telehealth session.
<b>Context</b>	Telehealth. Enables description of general purpose for which telehealth is used.
<b>Domain</b>	<ol style="list-style-type: none"> <li>1. Clinical care</li> <li>2. Education and/or training</li> <li>3. Management and/or administration</li> <li>4. Research and/or evaluation</li> <li>5. Health promotion and/or public health</li> <li>8. Other</li> </ol>
<b>Guide for use</b>	<p>Consulting or diagnostics should be recorded as domain item 1 “clinical care”.</p> <p>Supervision, mentoring, continuing professional education and distance learning should be recorded as domain item 2 “education and training”.</p>
<b>Source</b>	Nil

## 4. Defining Outcome Indicators – Why?

Within Canada, at least, there should be no question as to what a specific outcome indicator means and how it is measured.

### 4.1 Perspective

If six people are asked to define any outcome indicator, they will probably give six strikingly different definitions. This means that a crucial requirement in standardising outcome indicators will be to define each one. This type of standardisation is an often-ignored but extremely important process. During several recent activities, one study investigator (Scott) has conducted brief sessions with approximately 40 individuals to illustrate the importance of having clear and agreed upon definitions. It is of value to experience *firsthand* the basic results of this exercise in the context of this project.

***Take just 5 minutes to complete the exercise described below.***

StatsCan has definitions for many parameters that are studied on an ongoing basis. Four items that have some relevance to telehealth have been randomly selected: *Population; Urban Population; Total Mortality; Contact with Medical Doctors, and Doctors.*

In the spaces provided below, immediately write down your definition of these four ‘common’ indicators. Be clear but succinct. Once you have finished, compare your definitions to those provided by StatsCan (see pages 70 and 71).

### **Population**

Your definition:

### **Urban Population**

Your definition:

### **Total Mortality**

Your definition:

### **Contact with Medical Doctors**

Your definition:

### **Doctors**

Your definition:

Now turn to pages 69 and 70, and compare your definitions to those used by StatsCan. Some specific elements commonly missed have been underlined in the accepted definitions (one common error is to omit reference to some denominator), and some additional explanatory comments have been provided. It is most likely that you did not provide a response identical to the StatsCan definition – this is very, very common, and serves to highlight the need for clear and common definitions. The current lack of consistent definitions for outcome indicators and measured elements renders it dangerous to compare data collected in one setting to that collected in another. The old adage of GIGO – Garbage In; Garbage Out – comes to mind.

### SECTION 3

## *A Synthesis of the Telehealth Outcomes Literature*

**“In common with other industrialised countries, Canada is struggling with how to optimise the impossible triad of health care objectives: quality, accessibility, and affordability”.**

***(David Naylor, 2000)***

## 5. Telehealth Outcomes Literature - Process

### 5.1 Outcome Indicator Identification

#### 5.1.1 Literature Search Strategy

Search Limits: Publication date from 1985/01/01 onwards (except where noted); all English language articles, plus non-English articles with abstracts only.

Databases: For each database searched, unless otherwise indicated, telemedicine terms were combined with outcome indicators terms as shown. A search for additional grey literature was done using the Google ([www.google.com](http://www.google.com)) search engine and combinations of terms outlined in the PubMed/Medline.

Notes: a) Subject terms were “exploded” and so include additional narrower subject headings; b) asterisks (\*) indicate truncated terms.

#### o Pub Med/Medline (1985 to present)

##### Group A: Telemedicine Terms

ehealth] OR e-health[Title Words]  
emedicine OR e-medicine[Title Words]  
remote consultation[Subject/Title Words]  
telecommunications OR computer communication networks AND (medicine OR health) [Subject/Title Words]  
telecare[Title Word]  
teleconsultation[Title Word]  
telegeriatric\*[Title Word]

telehealth[Title Word]  
telematic\*[Title Word]  
telemedical[Title Word]  
telemedicine[Subject/Title Word]  
telemetry[Subject/Title Word]  
telemonitor\*[Title Word]  
telepathology[Subject/Title Word]  
telepsychiatry[Title Word]  
teleradiology[Title Word]  
teleconsult\*[Title Word]  
telescreen\*[Title Word]

##### Group B: Outcome Indicator Terms

access[Title Word]  
acceptability[Title Word]  
accessibility[Title Word]  
assess[Title Word]  
assessment[Title Word]  
cost\*[Title Word]  
cost benefit analysis[Subject]  
costs and cost analysis[Subject]  
evaluation\*[Title Word]  
evaluation studies[Subject]  
health care evaluation mechanisms[Subject]

indicator\*[Title Word]  
outcome\*[Title Word]  
performance[Title Word]  
process assessment (health care)[Subject]  
quality[Title Word]  
quality assurance, health care [Subject]  
quality indicators, health care [Subject]  
satisfaction [Title Word]  
technology assessment, biomedical [Subject]  
treatment outcome [Subject]

#### o Embase 1988 to present

##### Group A: Telemedicine Terms

ehealth] OR e-health[Title Words]  
emedicine OR e-medicine[Title Words]  
remote consultation[Title Words]

telecommunication AND (medicine OR health) [Subject/Title Words]  
telecare[Title Word]  
teleconsultation[Title Word]

telegeriatric\*[Title Word]  
 telehealth[Title Word]  
 telematic\*[Title Word]  
 telemonitor\*[Title Word]  
 telemedical[Title Word]  
 telemedicine[Title Word]

telemetry[Title Word]  
 telepathology[Title Word]  
 telepsychiatry[Title Word]  
 teleradiology[Title Word]  
 teleconsult\*[Title Word]  
 telescreen\*[Title Word]

#### **Group B: Outcome Indicator Terms**

access\*[Title Word]  
 acceptability[Title Word]  
 assess[Title Word]  
 assessment[Title Word]  
 biomedical technology  
 assessment[Subject]  
 cost\*[Title Word]  
 economic evaluation[Subject]

evaluation[Subject/Title Word]  
 health care quality[Subject]  
 indicator\*[Title Word]  
 outcome\*[Title Word]  
 performance[Title Word]  
 quality[Title Word]  
 satisfaction[Title Word]  
 treatment outcome[Subject]

#### o **TIE Telemedicine Information Exchange Database [1991 to present]**

As this is a telemedicine database, it was not necessary to combine outcome indicator terms with telemedicine terms to achieve the desired results.

#### **Outcome Indicator Terms**

access\*[Keyword]  
 acceptability[Keyword]  
 assess[Keyword]  
 assessment[Keyword]  
 cost\*[Keyword]  
 economic\*[Keyword]

evaluation[Keyword]  
 indicator\*[Keyword]  
 outcome\*[Keyword]  
 performance[Keyword]  
 quality[Keyword]  
 satisfaction[Keyword]

#### o **Cochrane Database of Systematic Reviews 1991 to 1<sup>st</sup> Quarter 2002**

As the Cochrane Database contains very few telemedicine systematic reviews and protocols, it was unnecessary to combine telemedicine terms with outcome indicator terms. Telemedicine records were retrieved and examined for relevance.

#### **Telemedicine Terms**

ehealth] OR e-health[Keywords/ Text Words]  
 emedicine OR e-medicine[Keywords/Text Words]  
 remote consultation[Keywords/Text Words]  
 telecommunication AND (medicine OR health) [Keywords/Text Words]  
 telecare [Keyword/Text Word]  
 teleconsultation [Keyword/Text Word]  
 telegeriatric\*[Keyword/Text Word]

telehealth[Keyword/Text Word]  
 telematic\*[Keyword/Text Word]  
 telemonitor\* [Keyword/Text Word]  
 telemedical[Keyword/Text Word]  
 telemedicine [Keyword/Text Word]  
 telemetry [Keyword/Text Word]  
 telepathology [Keyword/Text Word]  
 telepsychiatry [Keyword/Text Word]  
 teleradiology[Keyword/Text Word]  
 teleconsult\*[Keyword/Text Word]  
 telescreen\*[Keyword/Text Word]

#### o **PsychINFO (1985 to present)**

#### **Group A: Telemedicine Terms**

ehealth OR e-health[Title Words]  
 emedicine OR e-medicine[Title Words]  
 remote consultation[Title Words]

telecare[Title Word]  
 telecommunications media or teleconferencing AND health [Subject/Title Words]

teleconsult\*[Title Word]  
 teleconsultation[Title Word]  
 telegeriatric\*[Title Word]  
 telehealth[Title Word]  
 telematic\*[Title Word]  
 telemedical[Title Word]  
 telemedicine[Title Word]

telemetry[Subject/Title Word]  
 telemonitor\*[Title Word]  
 telepathology[Title Word]  
 telepsychiatry[Title Word]  
 teleradiology[Title Word]  
 telescreen\*[Title Word]  
 teletherapy[Title Word]

#### Group B: Outcome Indicator Terms

access[Title Word]  
 acceptability[Title Word]  
 accessibility[Title Word]  
 assess[Title Word]  
 assessment[Title Word]  
 cost\*[Title Word]  
 costs and cost analysis[Subject]  
 economics[Subject]  
 evaluation\*[Subject/Title Word]

indicator\*[Title Word]  
 mental health program evaluation[Subject]  
 outcome\*[Title Word]  
 performance[Title Word]  
 quality[Title Word]  
 quality of care[Subject]  
 satisfaction[Title Word]  
 technology assessment[Text Words]  
 treatment outcomes[Subject]

- o **DARE Database of Reviews of Effectiveness 1994 to present**
- o **NHSEED NHS Economic Evaluations Database 1994 to present**
- o **University of York HTA Health Technology Assessment Database [1994 to present]**

These three databases all use Medline Mesh subject headings. The search strategy is identical for all three and mirrors the PubMed/Medline search.

#### Group A: Telemedicine Terms

ehealth] OR e-health[Title Words]  
 emedicine OR e-medicine[Title Words]  
 remote consultation[Subject/Title Words]  
 telecommunications OR computer communication networks AND (medicine OR health) [Subject/Title Words]  
 telecare[Title Word]  
 teleconsultation[Title Word]  
 telegeriatric\*[Title Word]

telehealth[Title Word]  
 telematic\*[Title Word]  
 telemedical[Title Word]  
 telemedicine[Subject/Title Word]  
 telemetry[Subject/Title Word]  
 telemonitor\*[Title Word]  
 telepathology[Subject/Title Word]  
 telepsychiatry[Title Word]  
 teleradiology[Title Word]  
 teleconsult\*[Title Word]  
 telescreen\*[Title Word]

#### Group B: Outcome Indicator Terms

access[Title Word]  
 acceptability[Title Word]  
 assess\*[Title Word]  
 cost\*[Title Word]  
 cost benefit analysis[Subject]  
 costs and cost analysis[Subject]  
 evaluation\*[Title Word]  
 evaluation studies[Subject]  
 health care evaluation mechanisms[Subject]  
 indicator\*[Title Word]

outcome\*[Title Word]  
 performance[Title Word]  
 process assessment (health care)[Subject]  
 quality[Title Word]  
 quality assurance, health care[Subject]  
 quality indicators, health care[Subject]  
 satisfaction[Title Word]  
 technology assessment, biomedical[Subject]  
 treatment outcome[Subject]



o **EconLit 1985 to present**

**Group A: Telemedicine Terms [ehealth] OR e-health[Text Words]**

emedicine OR e-medicine[Text Words]	telemedical[Keyword/Text Word]
remote consultation[Text Words]	telemedicine[Keyword/Text Word]
telecommunication and (health* or medicine)[Keywords]	telemetry[Text Word]
telecare[Text Word]	telemonitor*[Text Word]
teleconsultation[Text Word]	telepathology[Text Word]
telegeriatric*[Text Word]	telepsychiatry[Text Word]
telehealth[Text Word]	teleradiology[Text Word]
telematic[Keyword/Text Word]	teleconsult*[Text Word]
	telescreen*[Text Word]

**Group B: Outcome Indicator Terms**

access	evaluate
accessibility	evaluation*
assess	health economics
assessment	indicator*
cost	outcome*
cost benefit*	performance
cost effectiveness	quality
cost utility	quality of care
economics	satisfaction

**5.1.2 Article Abstraction Process**

A total of 250 abstracts were reviewed with respect to telehealth outcome indicators, and 110 articles were subsequently read by the researchers, and data abstracted by the Research Assistant into 13 different categories included in an Excel chart. There was a 14<sup>th</sup> category that allowed for 'other' important definitions or information to be considered or additional information to be continued from an existing category. The 13 categories included in the Excel chart were:

- Author / Title / Journal / Year / Country
- Purpose / Objective
- Modality [Audio only; audio-video; audio video (data/ image)]
- Delivery [Live; Store-and-Forward]
- Technology [telephone system (specify- POTS; ISDN; ADSL); Internet; Wireless; MPEG; Satellite]
- Category of e-Health Application
  - The five e-health applications were **C**linical, **R**esearch, **E**ducation, **A**ministrative, and **M**ixed (**CREAM**).
- Study Design [experimental; quasi-experimental; non-experimental; descriptive]
- Findings - the findings were noted to be positive, negative, or mixed
- Outcome focus
  - This included patient, provider, facility, system, and / or society
  - May also be considered perspective
- Outcome Category: **Quality** (of Care and/or Life; Safety; Efficacy)
- Outcome Category: **Access**
- Outcome Category: **Acceptability**
- Outcome Category: **Cost**

### **5.1.3 Working Definitions**

Prior to the process of data abstraction, working definitions were required to identify which papers described outcome indicators in relation to one of the chosen categories. These were identified from the IOM model (Field, 1996) for quality of care, access, acceptability, and cost, viz:

**Quality (of care):** the degree to which the health care services for individuals and populations increases the likelihood of desired health outcomes and are consistent with current professional knowledge.

**Access:** the timely receipt of appropriate care, or the ease or difficulty in obtaining care, or the availability of the right care at the right time without undue burden.

**Acceptability:** the degree to which patients, clinicians, or others are satisfied with a service or willing to use it.

**Cost:** the economic value of the resource use associated with the pursuit of defined objectives or outcomes.

### **5.1.4 Outcome Category Analysis**

Beyond the search for an amalgamation of definitional material, each outcome category was examined in detail using qualitative content analysis that looked for themes and commonalities within each category. For example, within the category 'cost', all articles discussing cost were compiled and examined separately. During this process, any other additional definitions were identified, and an in-depth analysis was done looking for specific examples of cost in an effort to allow for comparison between different studies.

The specific methods of data collection described in studies for each outcome category were also considered important. Therefore, if a questionnaire was administered to a selection of patients in a study designed to measure patient satisfaction, particular attention was paid to whether or not the study included sample questions from that satisfaction questionnaire. The quality of the questionnaire itself is not currently being judged; however, the inclusion of sample questions allows some superficial evaluation of the quality of the methodology. For example, review of sample questions might provide some assessment validity, that is, were the questions truly measuring what they said they were measuring? Also, sample questions have been collected and reported here in an effort to compile a list of questions for review as efforts are made to develop definitional material.

### **5.1.5 Outcome Indicator Definitions**

To lay the groundwork for future efforts to define any candidate outcome indicator, each article was examined with particular focus on identifying and extracting any specific definitions. These definitions were compiled for each category. The criteria used to identify the definitions for each category rested on the notion that definitions had to be specific. That is, 'cost effectiveness' could not be defined through examples; rather, the study had to clearly state that 'cost effectiveness was defined as ...', or alternatively refer to something similarly concrete. Merely providing examples of a concept could not be used as a definition because of the variation in examples within each study.

### *Primary and Secondary Definitions*

It was found to be of value to divide the definitions into 2 categories: primary and secondary.

- **Primary** definitions were identified as those for which a discrete word or phrase was defined in a study. Primary definitions include access, acceptability (satisfaction), quality, safety, effectiveness, efficacy, and cost (including cost benefit analysis, cost effectiveness analysis, cost utility analysis, cost comparison, and cost minimization analysis).
- **Secondary** definitions were identified as those terms related to each outcome category, but not a definition of the actual word. Some examples of secondary definitions include: economic evaluation, direct and indirect costs, and continuity of care.

## 6. Telehealth Outcomes Literature - Results

Each of the following sections of the report is similarly described. Descriptive statistics regarding the literature are provided first, followed by description of any primary and secondary definitions identified. Thereafter, a discussion follows that describes aspects of the literature in relation to the specific category.

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### 6.1 *Quality*

#### 6.1.1 *Descriptive Statistics*

Of 110 total articles, 33 (30%) examined quality with respect to telehealth / telemedicine. For this analysis various aspects of quality were included: quality of care, quality of life, safety, and efficacy. Quality itself is defined broadly in terms of related characteristics, other than time, which may influence the experience obtained from using telehealth (Hailey and Jacobs, 1997). Multiple aspects of quality were measured in the 33 articles with numerous effects being examined, and assessments conducted.

The most common way to measure quality was through the use of questionnaires; twelve articles used questionnaires to assess quality. Questionnaires were instruments used to measure aspects or domains of, for example, experiences of psychiatric interviews (Dongier *et al.*, 1986), dimensions of family functioning (Pelletier-Fleury *et al.*, 1999), and patient health status (Ades *et al.*, 2000). Three articles used telephone and/or in person interviews, one article conducted a needs assessment identifying positive and negative aspects of telehealth using focus groups (Siden, 1998), and another article did a content analysis to address three program evaluation questions in relation to self-care (Closson *et al.*, 1994).

#### 6.1.2 *Definitions*

➤ Primary Definitions:

*Quality*: defined broadly to include those characteristics other than time that influence people's experience of telemedicine. (Hailey *et al.*, 1999).

*Quality* is defined as those relevant characteristics, other than time, which influence the experience obtained from the use of telehealth. (Hailey and Jacobs, 1997).

*Safety*: may include issues such as the risk of wrong diagnostic and management decisions as a consequence of using the technology. Appraisal of safety should also take account of issues related to existing services, such as the risk to some patients through delayed treatment if telemedicine were not available. (Hailey *et al.*, 1999).

*Safety*: include such issues as the risk of wrong diagnostic management decisions as a consequence of using the technology. (Hailey and Jacobs, 1997).

*Efficacy*: performance under optimum conditions; might be considered as the performance under carefully applied and monitored protocols, such as those used in pilot projects. (Hailey *et al.*, 1999).

*Efficacy*: might be considered as the performance of the technology, after an initial “learning curve”, under carefully applied and monitored protocols, such as those applied in pilot projects. (Hailey and Jacobs, 1997).

*Effectiveness*: relates to the application's performance after it has been adopted for routine use; may include patients' satisfaction, and reliability of equipment. (Hailey *et al.*, 1999).

*Effectiveness*: relates to how well the technology will perform after it has been adopted for routine use; may include users' and patients' satisfaction, generalisability of data from pilot studies. (Hailey and Jacobs, 1997).

➤ Secondary Definitions:

*Continuity of Care*: referred to the fact that a doctor has a good medical records system, or that a patient visits the same doctor for years, and thus the doctor knows a lot more about the patient than would otherwise be the case (Burghraeve and De Maeseneer, 1995).

*Comprehensive Care*: referred to the fact that primary health care should take into account the whole human being and not just an organ, or just the physical patient. It also referred to cooperation between providers of care and the cooperation between doctor and patient (Burghraeve and De Maeseneer, 1995).

*Self-Care*: included activities an individual initiates and performs to maintain life, health, and well-being (Closson *et al.*, 1994).

### **6.1.3 Discussion**

#### **6.1.3.1 Specific Tools**

The aspects of quality that have been measured are broad, but commonly, aspects of quality were measured using specific questionnaires. Examples of specific tools include, the ‘Coping Response Indices-Revised’ scale (Sandgren *et al.*, 2000), and the SF-36 questionnaire (Jerant *et al.*, 2001). The latter assesses general health status, and has been used in a wide variety of populations, and allows comparison of the impact of various diseases or interventions on self reported health status. Table 4 provides a list of all specific questionnaires used to assess quality that were identified in the abstracted references.

Of these 15 tools, 8 measured specific aspects of quality such as: family functioning, burden of caregivers, patient health status, coping, distress, quality of life, and health status. Other tools contributed important measures in the study of quality. Moreover, articles that did not use questionnaires but instead discussed either different methods of data collection, or did not state methods used, provide additional examples of indicators and measures.

<b>Table 4. Quality — Survey Tools Identified</b>	
<b><i>Tool</i></b>	<b><i>Factors Assessed / Measured</i></b>
<b>The Family Assessment Device (FAD)</b> (Brown <i>et al.</i> , 1999)	➤ Assessed 6 dimensions of family functioning: problem solving, communication, affective responsiveness, affective involvement, behavioural control, role dimension
<b>The Caregiver Burden Inventory (CBI)</b> (Brown <i>et al.</i> , 1999)	➤ Measures 5 dimensions of burden: developmental, physical, social, emotional, time dependence
<b>Health Status Questionnaire (measuring quality of life)</b> (Ades <i>et al.</i> , 2000)	➤ Measures 8 domains of patient health status: general health perceptions, physical function, role limitations—physical, role limitations—emotional, social function, mental health, bodily pain, energy/fatigue
<b>The Coping Response Indices-Revised Scale</b> (Sandgren <i>et al.</i> , 2000)	➤ Measures coping
<b>Profile of Moods States (POMS)</b> (Sandgren <i>et al.</i> , 2000)	➤ Measures distress: anxiety, depression, vigour, fatigue, anger, and confusion
<b>The Medical Outcome Scale</b> (Sandgren <i>et al.</i> , 2000)	➤ Measures quality of life in 6 areas: physical functioning, role functioning, social functioning, mental health, physical health, and pain
<b>SF-36 Questionnaire</b> (Jerant <i>et al.</i> , 2001)	➤ Assesses and scores health status in eight health domains in a wide variety of populations and allows for a comparison of the impact of a variety of diseases on health status
<b>Minnesota Living with Heart Failure Questionnaire (MLHFQ)</b> (Jerant <i>et al.</i> , 2001)	➤ Detects quality of life changes in pharmaceutical intervention trials
<b>Short-form McGill Pain Questionnaire</b> (Rybarczyk <i>et al.</i> , 1999)	➤ No details provided in paper. [21-item self-administered questionnaire. Used to measure patients' perceptions of the effects of congestive heart failure on their lives.]
<b>Beck Anxiety Inventory</b> (Rybarczyk <i>et al.</i> , 1999)	➤ No details provided
<b>Center for Epidemiologic Studies Depression scale</b> (Rybarczyk <i>et al.</i> , 1999)	➤ No details provided
<b>Multidimensional Health Locus of Control Scale</b> (Rybarczyk <i>et al.</i> , 1999)	➤ No details provided
<b>Abbreviated Health-Promoting Lifestyle Profile</b> (Rybarczyk <i>et al.</i> , 1999)	➤ No details provided
<b>Mental Health Inventory</b> (Kennedy and Yellowlees, 2000)	➤ No details provided
<b>Health of the Nation Outcome Scale</b> (Kennedy and Yellowlees, 2000)	➤ No details provided

### 6.1.3.2 Aspects of Quality Measured

#### *Beyond the Questionnaires*

Unlike the other outcome categories the aspects measured for *quality* do not fit 'neatly' under a series of headings. For example, in the outcome category *satisfaction*, the aspects measured include patient-physician interaction and preference between telemedicine and face-to-face, and various examples then clearly fall under those headings. Such clear categorisation is not feasible for *quality*. Consequently all of the various aspects identified as measures of *quality* (quality effects, evaluation, assessment, effectiveness, self-care, self-efficacy, quality and confidentiality, quality indicators, experience, and value) are listed and described below.

#### ⇒ *Quality Effects*

Bashshur (1995) discusses *quality effects* in telehealth which can either be technical or interpersonal in nature. Technical effects pertain to the process of care and its outcome, including continuity and coordination of care, timeliness, specialist consultation, and a "built in" second opinion. Interpersonal effects relate to the personal treatment and satisfaction of both provider and client.

#### ⇒ *Evaluation*

A study that evaluated a Remote Consultative Network (RCN) in Alberta (Jennett *et al.*, 1995) identified objectives of the evaluation in terms of quality as:

- To determine whether or not the RCN affected
  - diagnostic, investigative, and management decisions
  - feelings of professional isolation and educational opportunities
  - overall health of the patient
- To compare the RCN with traditional consultative methods.

Interviews were used in an effort to assess the impact on feelings of professional isolation and educational opportunities. Questions asked to respondents include: Is feedback from this type of encounter helpful from an educational point of view?

#### ⇒ *Assessment*

Identified in the literature on quality are three different types of assessment: needs, quality, and effectiveness.

- Needs Assessment (Siden, 1998)  
Focus groups were conducted with participants in this needs assessment to identify positive and negative aspects of telehealth. Positive aspects of telehealth were identified as: reduced travel burden for families, the potential for professional education from formal presentations and informal contact during consultations, and improved collaboration between professionals in the two locales.  
Negative aspects of telehealth were often expressed in terms that did not target specific criticisms of the system, but instead conveyed general areas of concern, for example, medical-legal liability.
- Quality Assessment (Hagan *et al.*, 2000)  
This study examined core criteria in the assessment of the quality of health-care with respect to the Info-Santé service. This included the speed with which the service can be delivered, and the optimum allocation of resources according to

medical needs. The quality of service provided depended on the adequacy of the response from participants who were users of the service.

Indicators used were, perception of:

- the nurse's level of understanding of the problem concerned
- the level of clarity of the language used by nurse to convey info and advice
- the level of comprehensibility of the info and advice provided
- the level of suitability of the solutions suggested
- the level of politeness or courteousness shown during the call
- the level of assistance offered in choosing solutions to the problem concerned.

The outcomes of the nurses' interventions were:

- anxiety reduction
  - feeling of self-empowerment behaviour deemed useful and effective in solving or stabilizing the problems
  - perception of advantages in resorting to Info-Santé rather than another available resource
  - direct or indirect savings made by the use of the service
  - the level of implementation of care and treatment; knowledge acquisition
  - overall usefulness; general satisfaction
- Effectiveness assessment (Harno *et al.*, 2000)  
This study looked at the effectiveness of telehealth in terms of diagnostic effectiveness (changes in or confirmation of diagnosis), and therapeutic effectiveness (changes in management as a result of teleconsultation).

#### ⇒ *Effectiveness*

Two studies, Hailey and Jacobs (1997) and Ohnima *et al.* (1999), studied quality in terms of effectiveness. For Hailey and Jacobs (1997), measures of effectiveness in relation to *quality* included: users' and patients' satisfaction, generalisability of data from pilot studies, support for users, and reliability of equipment (for example, measures of length of hospital stay, number of prescriptions, repeat consultations, and satisfaction with service). Ohnima *et al.* (1999) briefly mention clinical, diagnostic, and therapeutic effectiveness.

#### ⇒ *Self-Care*

Closson *et al.* (1994) argue that self-care includes activities an individual initiates and performs to maintain life, health, and well-being. In an effort to assess a telephone follow-up program, the primary program evaluation question was: "How effective is the discharge preparation of patients and caregivers in the rehabilitation setting?" Content analysis addressed three program evaluation questions: 1. What problems are encountered by the patient or caregiver after discharge? 2. What helping interventions do nurses apply during telephone follow-up calls with the patient or caregiver? 3. What are some examples of helping intervention in each problem area (e.g. medication)? The terms for nursing helping methods that were used in the program evaluation were: acting or doing for; guiding; supporting (physically or psychologically); providing a developmental environment; and teaching.

#### ⇒ *Self-Efficacy*

Piette *et al.* (2000) developed a scale to measure diabetes self-efficacy, which included questions regarding patients' confidence about their ability to perform aspects of diabetes self-care. Intervention patients responded to questions regarding



their experience with the automated telephone disease management (ATDM), and questions regarding the nurse follow-up. Questions included:

- did the ATDM calls make them more certain their doctor knew how they were doing?
- would they be more satisfied with their health care if ATDM was available to patients?
- would they choose to receive such calls if they were offered?
- did they learn something about their self-care?

⇒ *Quality and Confidentiality*

Woods *et al.* (1999) asked open ended questions pertaining to:

- Quality:
  - The telemedicine clinic is the same as the doctor being there.
- Confidentiality:
  - It is a unique experience with the technology involved
  - I don't like seeing myself on the television (negative comment)
  - I can tell the doctor exactly what I want as if she is in my presence

⇒ *Quality indicators*

Three quality indicators regarding the use of remote video technology in the home care setting (Johnston *et al.*, 2000) include:

- patient's compliance with medication regimen
- knowledge about their disease
- ability to move toward self-care

⇒ *Experience*

A study done by Dongier *et al.* (1986) used a questionnaire to measure patients and consultant's experience of psychiatric interviews compared with other interviews they had had. Aspects of importance in regards to the psychiatric interview were:

For patients:

- ability to express oneself
- feeling at ease
- feelings after termination of the interview
- did they perceive the psychiatrist as feeling at ease or not?
- quality of the interpersonal relationship
- will the interview help in their treatment

For consultants and consultees:

- the preliminary discussion between consultant and consultee
- patient/consultee or patient/consultant relationship
- post interview discussion
- written conclusions for diagnosis, management, and treatment
- global evaluation of the usefulness of the interview

⇒ *Value of telemedicine*

Measures proposed to enhance value of telemedicine, argued by Charles (2000) include:

- establishment of regulations to address interstate licensure and credentialing of care providers

- legislation to ensure security of personal health information
- payment for the entire range of telemedicine applications
- access to high-quality health information for providers and patients with guarantees of authentication, access control, confidentiality, and integrity of the information

#### **6.1.4 Conclusion**

The list of questionnaires described for 'quality' is of importance. No other outcome indicator category showed such a prevalence of specific tools. This highlights the lack of validated tools that exist for evaluation of telehealth in the remaining categories, and represents an example of where validated tools could be introduced for consistent evaluation of telehealth.

Quality of care, however, may also be measured in ways other than the administration of questionnaires. The dimensions of quality, as identified in the literature, are varied. Some of them include: the process of care, the personal treatment of a client, and the quality of service provided by a specific telephone system where nurses answered calls about the concerns clients had about health care. In the particular case, quality related to issues such as clarity, comprehensibility, and politeness shown to clients during a call.

Quality also appears to relate to effectiveness, which can indicate many things including satisfaction, reliability of equipment, and confirmation of diagnosis. Additionally, making sure individuals are supported after release from hospital, or that they are confident in their ability to perform aspects of self-care are also part of quality of care. Confidentiality is also a significant part of quality. Individuals need to feel and should expect that their health information is, and will be, protected.



## **6.2 Access**

### **6.2.1 Descriptive Statistics**

The number of articles looking at the category access is substantially smaller than the number for costs, acceptability and quality. Of 110 total articles, a mere 14 (13%) discuss access. Broadly, access refers to the relative ease or difficulty in obtaining health services (Bashshur, 1995). More specifically, in a study done by Jennett *et al* (1995), access to health services as it pertains to clinical consultations between health care providers addressed two issues: *timeliness and convenience* of attending clinical consultations, and the *breadth of consultation services available*.

### **6.2.2 Definitions**

#### ➤ Primary Definitions

*Bashshur (1995):* Access refers to the relative ease or difficulty in obtaining health services. From the client's perspective it is defined in terms of the extent to which they face geographic, economic, architectural, cultural, and/or social barriers to needed care. For providers in both remote and central sites, it relates to convenience, opportunity cost, and workload. From a societal perspective, improved access to care may increase overall level of satisfaction with life in the rural community, thus improving the quality of life in rural communities.

*Burghgraeve and De Maeseneer (1995)*: accessibility of care in literature reviewed by these two authors refers to the fact that primary health care is intended to be available to all people at the moment they decide they need help because they are feeling ill.

#### ➤ Secondary Definitions

Access to health services as it pertains to clinical consultations between health care providers addresses two issues: timeliness and convenience of attending clinical consultations, and breadth of consultation services available (Jennett *et al.*, 1995).

### **6.2.3 Discussion**

Although general themes within access can be identified (and will be discussed below), access means different things to various stakeholders in the health care system, thus representing diverse perspectives. Although perspective is noted most commonly in the outcome category of 'cost', the perspectives of client, provider, and society are reviewed here.

#### Perspective

##### ❖ Client

Bashshur (1995) argues that from the client's perspective, access is defined in terms of the extent to which they face geographic, economic, architectural, cultural and/or social barriers to required care.

##### ❖ Provider

For those providers in remote and central cities, access is related to convenience, opportunity cost, and providers' workload.

##### ❖ Society

Finally, from a societal perspective, improved access to care may increase the general satisfaction with life in rural communities, which would have an impact in the improvement of the quality of life for those living in a rural community.

#### Accessibility

Accessibility (of care) was defined in two articles.

- Burghgraeve and De Maeseneer (1995) did a review of the literature and concluded that accessibility of care refers to the fact that primary health care is intended to be available to all people at the moment they decide they need help because they are feeling ill.
- A study done by Hagan *et al.* (2000) concerning the accessibility and quality of service provided by Info-Santé, a telephone health line nursing service available in Québec, provides a most exceptional example, not only of accessibility, but also of satisfaction, access, and cost, of how definitions relate specifically to the study being conducted.

In this study, accessibility was defined as the ability of users (callers), first, to get quick access to the Info-Santé system, and second, to obtain, directly from nurses, a response to their needs. Assessing accessibility refers to the users' perception of the obstacles encountered in achieving both of these objectives. The perception of callers was based on

two categories of potential obstacles: level of complexity in obtaining the Info-Santé service telephone number, and the number of attempts necessary to get through; time taken to achieve this communication; the problem of having to speak to a number of people or to an answering service before being able to speak directly to a nurse; and non-immediate access to a nurse who is able to speak the caller's language adequately.

### Time

A prevalent theme identified in the category *access* is time (e.g. Hagan *et al.*, 2000). Issues of time include:

- Timeliness
- Turn around time
- Open ended question: 'I like telehealth because it is quick, I don't have to wait so long'
- Time taken to achieve communication over telephone with a nurse
- Reduced travel time
- In a simple time benefit analysis, time considerations included: patient and physician travel time, loss of work for the patient, accommodation charges for the patient or physician

### Sample Questions: Access

Note: these are not a complete list of questions asked with respect to access, but represent merely a selection.

Jennett *et al.* (1995:73)

- Access to health services from rural areas: Do you feel this consultive service will affect the health care of the rural community?
- Do you feel this system may have an impact on rural physicians?
- Do you feel this system may have an impact on rural patients' families or support systems?
- Do you think this system may have an impact on the patient's health status?

Woods *et al.* (1999)

- I've been receiving good service, with TM things are out in the open
- The doctor is not there but the clinic is still good
- I like TM because it is quick, I don't have to wait so long

## **6.2.4 Conclusion**

Access is a multidimensional concept representing:

1. The ease with which health services are initiated
2. The ease with which health services are sustained
3. The amount of time it takes to access those health services
4. How easily one, most often the patient, can obtain information regarding health services

Conceptual domains of access include:

- a) affordability
- b) acceptability
- c) accommodation
- d) availability

- e) service diversity
- f) competitive stance

Generally, accessibility to health care implies that some people may have access to health services while others may not. This is applicable in various contexts including rural and urban settings where there may be transportation issues, or where there may be financial difficulties for clients. It may also be the case that the issues described above are related. For example, if a patient in a rural community has inadequate health care services in the area may require that a family member or friend drive them to a hospital for the needed services. It is not uncommon that such an arrangement will require that the family member or friend to drive the patient to the other location during work hours. As such, having to rely on family members or friends due to inadequate health care services in ones area may impose a financial burden to those responsible for transportation.

Both issues of poor transportation and inadequate financial resources may be considered barriers to health care services. The literature reviewed however, does not use the term 'barriers'. The closest references to barriers are 'obstacles' identified in the study on Info-Sante. The issues identified in the literature that relate to access include: timeliness, reduced travel time, and ability to gain access to information from a nurse. Interestingly, one aspect of access not identified was equity of access, that is, was there a difference between urban and rural access to health care services, or between different age groups, or families with different financial status? The availability of service is one issue, but equity of access must also be considered.



## 6.3 Acceptability

### 6.3.1 Descriptive Statistics

Of one hundred and ten articles examined for outcome indicators, forty-seven (43%) addressed the outcome category acceptability, or satisfaction. Various data collection methods were identified in the articles, but most focused on the administration of surveys or questionnaires. Of the 47 articles discussing acceptability, there were 36 (86%) that either used or suggested using questionnaires or surveys, 6 (13%) where there was no information provided or the data collection method was unclear, 2 (0.04%) using telephone interviews, 2 (0.04%) articles that did a literature or systematic review, and one article (0.02%) used a structured interview and one other used a semi-structured informal interview.<sup>1</sup> The majority of questionnaire responses were rated on 3, 5, 7, or 10 point Likert (or Likert-type) scales, but most commonly, items were rated on 5-point Likert scales.

The range of satisfaction measured is broad; however, questionnaire design, even when faulty in its applicability, focuses on users of telemedicine services: primarily patients and providers. It appears as though patient satisfaction questionnaires are not truly and exclusively measuring, for example patient, satisfaction. That is, other areas of importance in terms of outcome indicators (most specifically access and quality) can be found within satisfaction questionnaires. The measure of acceptability is often very clear: articles state they did a patient satisfaction questionnaire, but what is less clear is what the satisfaction questionnaire aimed to measure.

<sup>1</sup> One article is counted here twice as they used triangulation of methods and did telephone interview and questionnaire.

There was a selection of articles that clearly stated what it was they were measuring in terms of satisfaction, but some were more detailed than others. For example, some articles noted that patient satisfaction was going to be measured with certain outcomes, but did not provide any sample questions. One patient satisfaction survey measured anxiety, ability to cope, assistance by a relative or friend, and the presence of any problems (Berkman et al., 1999). Another self-administered questionnaire examined outcome measures of patient satisfaction that were: confidence in the consultation, technical aspects of the consultation, and aspects surrounding confidentiality. However, other articles detailed what they measured and how they measured it by providing sample questionnaire questions. Moreover, these articles often used multiple outcomes to evaluate the measure of satisfaction.

### 6.3.2 Definitions

#### ➤ Primary Definitions

Dick *et al.* (1999): These authors had a variation on the concept of acceptability. *Comfort* was conceived of as a notion of the personal ease or absence of concern with the process or elements of consultations. *Satisfaction* was conceived of more broadly as the extent to which the goals of the consultation and needs of the individual have been met.

Hagan *et al.* (2000): *Satisfaction*: refers to the fulfillment of the expectations or perceived needs of an individual in a particular situation. Definition used was: A subjective perception of the service by the user, which health staff have to consider as representing reality, even though this perception may well not take into account the relevance of the intervention and its effectiveness upon the user's state of health (Megivern et al., 1992). Note: In Hagan et al's (2000) study of a telenursing service, these authors defined satisfaction as it pertained directly to their study, but the overall definition is useful in a broader sense.

#### ➤ Secondary Definitions

None identified.

### 6.3.3 Discussion

#### Aspects of Satisfaction Measured

Investigation into the aspects of satisfaction measured<sup>2</sup> in the 47 articles discussing satisfaction uncovered a vast array of health outcomes measured. Few studies concretely identified what was being measured (other than saying they sought to measure patient or physician satisfaction) and as a result, this suggests outcome measurements named in this study may be open to interpretation. Broadly, studies were concerned with measuring patient satisfaction with telemedicine which included: perceptions and attitudes about categories such as technology, privacy and confidentiality, preference between telemedicine and face-to-face care, and professional-patient interaction.

Table 5 below is a summary of the aspects of satisfaction measured. It includes measures and within each cell are either questions or statements rated by the participants that were part of a satisfaction questionnaire or interview where the questions or statements were included in the article itself. Areas of patient, parent, professional (the users of telemedicine) satisfaction are represented together.

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<sup>2</sup> The aspects of satisfaction measured in this study are unique; however, the categorisation follows a similar study done by Williams *et al.* (2001).

**Table 5: Aspects of Satisfaction Measured**

<p><b><u>Feelings/ Experiences and Comfort</u></b></p> <ul style="list-style-type: none"> <li>• The presence of the TV camera made me feel self-conscious</li> <li>• At the beginning/end of your consultation, how comfortable were you with the idea of speaking to your specialist though TM?</li> <li>• How comfortable were you during the assessment?</li> <li>• Whether they thought they could reveal their thoughts and feelings over the phone</li> <li>• Were comfortable with phone talks?</li> <li>• Comfort level speaking to nurse</li> <li>• Did you like talking to the doctor?</li> </ul>	<p><b><u>Professional-Patient Interaction</u></b></p> <ul style="list-style-type: none"> <li>• Explanation of what was done for you</li> <li>• Were you able to discuss things fully with your midwife?</li> <li>• The community midwife encouraged me to ask all the questions I wanted to ask</li> <li>• Clarity and understanding of the physician's activities</li> <li>• How well were you able to communicate with the patient and parent?</li> <li>• How easy was it for you to talk to the psychiatrist?</li> <li>• The consultant understood my problem</li> <li>• The potential for improving communication with the patient</li> </ul>
<p><b><u>Timeliness and Convenience</u></b></p> <ul style="list-style-type: none"> <li>• The appointment took longer than expected</li> <li>• Length of wait to get an appointment with a specialist</li> <li>• Convenience of the location of the hospital</li> <li>• Time spent in the consultation</li> <li>• How timely results were returned</li> </ul>	<p><b><u>Overall Satisfaction</u></b></p> <ul style="list-style-type: none"> <li>• The visit overall</li> <li>• Overall the amount of information given to you by the community midwife</li> <li>• How well do you think the assessment went?</li> <li>• How helpful do you think the assessment was?</li> <li>• Overall satisfaction with the care received from the nurse</li> <li>• Overall, I was satisfied with the telehealth system</li> </ul>
<p><b><u>Preference between FTF and TM</u></b></p> <ul style="list-style-type: none"> <li>• I would rather see a patient/specialist using the TM system now than wait a few days to see him/her in person</li> <li>• A teleconsultation is just as good as going to the out-patient clinic to see the dermatologist</li> <li>• Would you rather have a video examination with a psychiatrist or an in-person examination by a general practitioner who knows a little less about psychiatry?</li> <li>• If you lived 2 hours away from the hospital, would you rather travel to the hospital to see the psychiatrist, or go to a place close to home and see them by video?</li> <li>• Overall, which did you prefer?</li> <li>• The care I received from this consult was as good as an in person visit</li> <li>• Would you prefer using TM instead of travelling?</li> </ul>	<p><b><u>Privacy/Confidentiality</u></b></p> <ul style="list-style-type: none"> <li>• Do you feel your privacy was respected during the TM consultation?</li> <li>• Are you concerned that this system may make it easier for your private information to leak out?</li> </ul>

<p><b><u>Professional Competence/ Personal Manner</u></b></p> <ul style="list-style-type: none"> <li>• Surgeon's confidence in interacting by TM</li> <li>• Technical skills of the doctor you saw (thoroughness, carefulness, competence)</li> <li>• The personal manner of the doctor you saw (courtesy, respect, sensitivity, friendliness)</li> </ul>	<p><b><u>Technological</u></b></p> <ul style="list-style-type: none"> <li>• I could hear everything that was being said</li> <li>• Quality of transmission</li> <li>• Satisfaction with TM equipment</li> <li>• The technical effort necessary for conducting the TM service</li> <li>• How easy was it for you to see and hear the psychiatrist?</li> <li>• I could hear the interviewer well</li> <li>• The interview seemed very mechanical</li> </ul>
<p><b><u>Informativeness</u></b></p> <ul style="list-style-type: none"> <li>• Which one of the following best describes the way you obtained information from your community midwife?</li> <li>• Satisfaction with nurse's medical knowledge</li> </ul>	<p><b><u>Potential for Future Use/ Usefulness</u></b></p> <ul style="list-style-type: none"> <li>• The value of the teleconsultation for each individual case</li> <li>• Would you recommend any further investigations?</li> <li>• Was there anything you would like to have changed or improved?</li> <li>• Are you likely to use the telepsychiatry service in the future?</li> <li>• How satisfied were you with the health improvement for the client?</li> <li>• Would they recommend the program to a colleague?</li> </ul>

### Example Studies

The studies detailed below are included here to illustrate additional examples of the measure of acceptability.

- In a study done by Zollo *et al.* (1999) provider satisfaction with a telemedicine service was measured using a questionnaire that had 6 items to evaluate the following outcomes for each telemedicine encounter:

- usefulness for establishing a diagnosis
- value in developing a treatment plan
- appropriateness for specific medical conditions
- quality of transmission
- adequacy of telemedicine to complete the consultation
- satisfaction with telemedicine equipment

Within these outcomes are multiple measures: usefulness and value, appropriateness and adequacy, and technology.

- Other studies also make note of multiple measures of patient satisfaction and patient perception. Johnston *et al.* (2000) developed a survey to measure *patient satisfaction* and the survey emphasized technology and in-person encounters, and addressed:

- ease of use
- system reliability
- effectiveness and degree of provider interaction
- confidence in provider's ability to assess health conditions remotely
- appropriate level of care
- convenience



- access to care
- preferences

This study seeks to measure patient satisfaction; however, it is looking more at measuring issues of access and quality of care.

- A study done by Demiris *et al.* (2001) used the instrument TMPQ (Telemedicine Perception Questionnaire) to measure *patient perception* of telemedicine. The items in this questionnaire addressed the effect of telehomecare on:
  - quality of and access to health care
  - issues of time and money (including the time saving for the patient and/or nurse, reduction in costs of the patient and/or health care agency)
  - and factors related to the conduct of a virtual visit (including the ease of equipment use, equal acceptability of “virtual” and real visit, protection of privacy and confidentiality, lack of physical contact, reduced sense of intimacy, patient’s ability to explain medical problems in a virtual visit)

The measures of patient perceptions of telemedicine with respect to telehomecare are addressing issues of quality, access, cost, and technology.

- A 34-item structured interview instrument developed by Agrell *et al.* (2000) was used to assess *patients’ perceptions* of telemedicine. Below is a summary of the 6 categories of perceptions, and sample questions given to patients to evaluate each individual’s perception.

1. General considerations: global impressions of home telecare.

- How satisfied are/were you with the home telecare?

2. Technological considerations: perceptions regarding the use of technology in homecare and difficulty in operating the equipment.

- I found it hard to start the equipment when the nurse called me;
- I think there have been a lot of technical problems with the equipment.

3. Education and self care considerations: exchange of knowledge and effect on patient’s role in managing their disease(s).

- I got enough information via home telecare to understand my diagnosis;
- I have become more active in my health care since using home telecare.

4. Video considerations: importance of the video image and quality.

- Being able to see the nurse via video is important to me;
- If the video monitor was out of order, I would prefer to wait until it was repaired for my next nursing visit, even if it took several days.

5. Physical presence considerations: importance of actual physical presence of the provider in the home and the impact of its absence.

- There is a major difference between seeing my nurse on the video monitor and seeing them face-to-face.

6. Confidentiality considerations: degree of reassurance regarding confidentiality in disclosing information to providers.

- I have been concerned about whether the privacy of my personal medical information was protected;
- I would cancel an in-person home visit by a nurse if I had guests in my home;

- I avoid talking about very personal things over the equipment but would feel comfortable discussing such things with a nurse in my home.
- A systematic review of studies on patient satisfaction done by Williams, May, and Esmail (2001) provided a guideline for the analysis of categories with respect to patient satisfaction. In Table 1: Aspects of Satisfaction Measured, 10 categories were identified for the present study. They are:
  - Feelings/experiences and Comfort
  - Professional-Patient Interaction
  - Timeliness and Convenience
  - Overall Satisfaction
  - Preference between FTF and TM
  - Privacy and Confidentiality
  - Professional Competence/ Personal Manner
  - Technological
  - Informativeness
  - Potential for Future Use/ Usefulness

In the Williams *et al.* (2001) study, aspects of satisfaction measured were similar; however, this review only examined patient satisfaction, and did not include users of telemedicine services beyond that. The aspects are:

- Professional-Patient Interaction
- Patient's experience/ feeling
- Overall satisfaction
- Technical aspects
- Preferences between telemedicine and face-to-face
- Convenience
- Administrative aspects
- Physical environment

Despite identifying these categories, Williams *et al.* (2001) conclude that the evidence concerning patient satisfaction with telemedicine is limited in scope.

### **6.3.4 Conclusion**

A crucial element of success in terms of satisfaction is acceptability by its users. Ultimately, users must be satisfied with a service and / or willing to use it in order for it to be successful. Furthermore, users should be satisfied with telehealth when compared with regular care. From the literature it appears as though comfort, feelings, and the interaction of a patient with their physician are important aspects of satisfaction. The issue then becomes how much they accept it, for example, when compared to face-to-face care. Satisfaction further encompasses convenience, appropriateness, access, and reliability of equipment.

Patients' perception of telemedicine was measured in several studies, typically addressing such indicators as time, access, technology, confidentiality, and education and self care.

Impact and outcome indicators of 'satisfaction' would be those looking for evidence that the user participation activity resulted in measurable change (ideally for the better) for either the user or provider of the telehealth services.



## 6.4 Cost

### 6.4.1 Descriptive Statistics

Of 110 articles abstracted, 58 articles (53%) gave attention the outcome indicator, cost. Information provided in the articles varied from in-depth cost analyses, to a mention of a telemedicine service being cost effective. Of the 58 articles noting cost, 38 (64%) of those mentioned or listed (by providing specific examples) fixed, variable, direct, indirect, marginal, or general costs. In the 38 articles, the fixed, variable, direct, indirect, marginal and general costs included in or excluded from an analysis are noted 72 times (65 times for costs included and 7 times for costs excluded). Below is a table detailing these results (Table 6).

<b>Table 6. Fixed, Variable, Direct, Indirect, Marginal, and General Costs Included and Excluded in Articles</b>	
<b>Costs Included in Analyses</b>	<b>Number of Articles</b>
▪ Fixed	12
▪ Variable	13
▪ Direct	12
▪ Indirect	6
▪ General	17
▪ Marginal	5
<b>Costs Excluded in Analyses</b>	
▪ Fixed	0
▪ Variable	1
▪ Direct	0
▪ Indirect	1
▪ General	4
▪ Marginal	0

### 6.4.2 Definitions

#### ➤ Primary Definitions

##### 1. Cost Benefit Analysis (CBA)

- Cost benefit analysis uses standardized measures (in monetary terms) to compare costs and benefits (Bashshur, 1995).
- CBA is where all costs and benefits must be valued in a commensurate unit, such as money (McIntosh and Carins, 1997).
- The outcomes of the cost benefit analysis are always valued in monetary terms called benefits; cost benefit analysis yields, theoretically, the best results for resource allocation (Ohinmaa *et al.*, 1999).
- Goal is to identify whether a programme's benefits exceed its costs; a positive net social benefit indicating that a programme is worthwhile (Drummond *et al.*, 1997)<sup>3</sup>.

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<sup>3</sup> This reference is not an article, rather, Drummond *et al.* (1997) provides a well-known economic evaluation with respect to health care programmes.

## 2. Cost Effectiveness Analysis (CEA)

- Cost effectiveness analysis compares costs of rendering a measure of effectiveness (Bashshur, 1995).
- Allows for the comparison of alternatives in which both the costs and outcomes differ (Crowe, 1998).
- Is technical efficiency and unidimensional outcome (McIntosh and Carins, 1997).
- Compares the costs and health effects of at least two alternatives (Sisk and Sanders, 1998). (CEA/CBA should specify the full range of alternatives i.e. the source of evidence of efficacy, effectiveness to justify the relation between the intervention and the expected effect).
- The net difference in cost in relation to the net difference in outcome when comparing telemedicine with the alternative technique (Hailey *et al.*, 1999).
- The net difference in cost in relation to the net difference in outcome, when comparing telehealth with the alternative technology (Hailey and Jacobs, 1997).
- Concerns the relationship between project inputs, such as equipment costs and transmission costs, and project outcomes, where the outcomes are not monetary, and cannot readily be converted into dollars (Hayward and Mitchell, 2000).
- Assumes that the costs of the alternatives are equal and that they differ only in their effectiveness. This is a form of economic evaluation where the costs and effectiveness of alternatives are compared (Ohinmaa *et al.*, 1999).
- Analyses in which costs are related to a single, common effect which may differ in magnitude between the alternative programmes (Drummond *et al.*, 1997).

## 3. Cost Utility Analysis (CUA)

- CUA is a form of cost effectiveness where the basic outcome measure is in 'healthy years' (McIntosh and Carins, 1997).
- Focuses particular attention on the quality of the health outcome produced or averted by health programmes or treatments (Drummond *et al.*, 1997).

## 4. Cost Comparison (CC):

- Only the costs of telemedicine and the alternative technique are compared (Hailey *et al.*, 1999).
- Only the costs of telehealth and the alternative technology are compared (is a less complete analysis than cost effectiveness) (Hailey and Jacobs, 1997).

## 5. Cost Minimization Analysis (CMA):

- The outcomes or benefits are assumed to be similar, and alternative approaches that lead to the least costly program are evaluated (Agha *et al.*, 1999).
- The outcomes are assumed to be equal between the compared alternatives (Ohinmaa *et al.*, 1999).
- Where the consequences of two or more alternatives are examined alongside costs in the same study and are shown to be equivalent (Drummond *et al.*, 1997).

*Efficiency*: addresses the question of whether the technology is good value for the money (Hailey *et al.*, 1999).

➤ Secondary Definitions

*Economic Evaluation*: stresses efficiency, but in the course of assessing the cost implications of allocating resources, economic evaluations address health related outcomes of care and thus its quality and accessibility. It is usually a comparison of the costs and consequences of alternative ways of managing a condition (Sisk and Sanders, 1998).

*Economic Evaluation*: basic tasks are to identify, measure, value, and compare the costs and consequences of the alternatives under consideration (McIntosh and Cairns, 1997).

*Economic Evaluation*: the comparative analysis of alternative courses of action in terms of both their costs and consequences (Drummond *et al.*, 1997).

*Economic Evaluation*: at least two alternatives should be compared; assumes that the costs of the alternatives are equal and that they differ only in their effectiveness (Ohnima *et al.*, 1999).

*Diagnostic Effectiveness*: Changes or confirmation of diagnoses; *therapeutic effectiveness*: changes in management as a result of teleconsultation (Harno *et al.*, 2001). (In a cost benefit and cost minimization analysis, the assessment of the v/c application's effectiveness included both of these types of effectiveness).

*Efficiency*: achieving maximum benefit for least cost (McIntosh and Cairns, 1997).

*Equity*: concerned with who bears the costs and who receives the benefits (McIntosh and Cairns, 1997).

Direct Costs:

- The expenditures for goods, services, and other resources which are necessary to provide an intervention including its future consequences (Holle and Zahlmann, 1999).
- Include those directly attributable to the application of telemedicine or the conventional alternative (Hailey and Crowe, 2000).

Indirect Costs:

- Gains and losses in productivity which are associated with the intervention (Holle and Zahlmann, 1999).

Fixed Costs:

- Those costs which do not vary with the number of patients served (Bergmo, 2000).
- Do not vary according to the utilization of a produced service (Ohnima *et al.*, 1999).
- Costs which do not vary with the quantity of output in the short run (about one year) (Drummond *et al.*, 1987).

Variable Costs:

- Those costs which alter with the number of patients served (Bergmo, 2000).
- Costs that vary according to the level of service (Ohnima *et al.*, 1999).

#### Break Even Analysis/Point:

- Number of patients for which the cost of teleconsultation is the same as the cost of conventional consultation (Lamminen *et al.*, 2001).
- The annual fixed costs of telemedicine divided by the marginal savings associated with each telemedicine consult (Stensland *et al.*, 1999).
- Considers the volume of consultations needed for the total annual costs of the two types of services (telemedicine and its alternative) to be equal (Ohinmaa *et al.*, 1999).

#### Sensitivity Analysis:

- By modifying the value of one variable at a time within a reasonable estimate and holding all other variables constant, sensitivity analysis defines the effect on total cost, i.e. “sensitivity to change” for changes in the value of that variable (Agha *et al.*, 1999).

#### Marginal Cost:

- Cost of doing one more consultation (Loane *et al.*, 2001)
- Cost or benefit borne when one additional unit of product or service is produced (Ohinmaa *et al.*, 1999).
- The *extra* cost of producing *one* extra unit of output (Drummond *et al.*, 1997).

### **6.4.3 Discussion**

#### Economic Evaluation Methods

Table 7 details the number of articles that either did a specific type of economic evaluation, or that discussed a particular evaluation method. Methods include: cost effectiveness analysis, cost benefit analysis, cost utility analysis, cost analysis, cost comparison analysis, and cost minimization analysis. The total number of articles noting each type of cost is 27. (The number of articles conducting or discussing an analysis is higher than the total number of articles because some articles mention multiple types of analyses).

<b>Table 7. Economic Evaluation Methods Noted In Articles</b>		
<b><u>Method</u></b>	<b><u>Number of Articles Conducting * the Analysis</u></b>	<b><u>Number of Articles Discussing the Analysis</u></b>
Cost Effectiveness Analysis	5	10
Cost Benefit Analysis	3	5
Cost Utility Analysis	0	2
Cost Analysis	5	2
Cost Comparison Analysis	3	2
Cost Minimization Analysis	2	1

\*The quality of the study was not considered here, that is, if an article stated it conducted a 'cost effectiveness analysis', it was included.

#### Perspective

Ohinmaa *et al.* (1999) argue that the question of perspective is very important in every assessment study since “any item may be a cost from one point of view, but not from another”. Examples of perspectives include society, patient, provider, facility, and system. Sisk and Sanders (1998) argue that it is “essential that an assessment of the benefits and costs of telemedicine specify the perspective of the analysis”. Furthermore, McIntosh and

Carins (1997) suggest that any full economic evaluation of telemedicine should consider costs and benefits to various sectors of society, and thus take a “broad perspective and present a detailed breakdown of the costs and benefits to” decision makers, patients, clinicians, purchasers, and providers.

Of the 58 articles discussing cost, 3 stated which perspective was used, and an additional 6 articles noted the importance of considering perspective when doing an economic evaluation. In the three studies that stated a perspective, Bergmo’s (2000) study took a social and health care perspective and examined costs falling on the public health service. Charges were considered from the perspective of the health care system in Jerant *et al.*’s (2001) study; and a cost analysis done by Loane *et al.* (2001) was carried out from both a health service and a patient perspective.

### Sensitivity Analysis

When conducting an economic evaluation, results reflect both the data and methods used, and further, the environment in which they are derived. Ohinmaa *et al.* (1999) suggest that the practical interpretation of the results revolves around “sensitivity analysis in which cost and outcome factors are simulated under various basic assumptions”. A sensitivity analysis is mainly used to consider the element of uncertainty in an economic evaluation. Drummond *et al.* (1997) discuss four sources of uncertainty in economic evaluation, and why analysts’ may use sensitivity analysis. Furthermore, they suggest three steps involved in sensitivity analysis:

1. identify uncertain parameters for which sensitivity analysis is required
2. specify the plausible range over which uncertain factors are thought to vary
3. calculate study results based on combinations of the best guess, most conservative, and least conservative estimates.

For a detailed sensitivity analysis reviewed for this study, see Loane *et al.* (2001) and Stensland *et al.* (1999).

### Break-even Analysis

In the 58 articles that included cost information, there were 8 articles that either provided a specific number for the calculation of their break even point/number, or that discussed break even analysis. Various levels of detail were provided with respect to the break even point with some studies providing more detailed information than others. Break even numbers also varied, as did their points of reference which included kilometres traveled and number of consultations.

For example, Loane *et al.* (2000) reported that the costs of real-time and conventional consultations become equal when the round trip travel distance to the hospital was 74 km. The break even consultation rate was 396 consultations for Doze *et al.* (1999), and Bergmo (2000) found that telemedicine was the cheapest method for workloads above 195 a year. When examining cost savings for ophthalmology and dermatology patients who used telemedicine, Lamminen *et al.* (2001) found that the break even point, which was the number of patients for which the cost of teleconsultation is the same as the cost of conventional consultation, were more than 110 ophthalmology teleconsultations annually, and 92 patients for dermatology. Davis *et al.* (2001) found that telemedicine was more cost effective at higher volumes of service with this study’s break even rate reported at 247 consults per year.

## Direct, Indirect, Fixed, Variable, Marginal, and General Costs

### *Headings, Categories, and Examples*

The following table (Table 8)<sup>4</sup> is a summary of articles that *included* in their analyses fixed, variable, direct, indirect, and marginal costs. Some studies further noted costs that were *excluded* from analysis (Table 9). The studies that did not detail what types of costs were included or excluded (fixed, variable, direct, indirect, and marginal) are labelled as general costs. For example, some articles simply noted “costs to be considered” (Friedman *et al.*, 1996) or “variables employed in the analysis” (Whitten *et al.*, 2000). (An attempt has been made to mention each type of cost within each category only once, but to include all variations. For example, if one article includes travel cost, and another patient travel cost, both will be included).

Different types of cost, for example, travel costs or annual line charges or salaries and wages, are often presented in multiple cost categories, including both fixed and variable costs. The different types of cost can be grouped into broader headings within each cost category. For example, travel costs fall under the broader heading travel, and annual line charges are an example of communication costs. The headings travel and communication costs are composed of several examples, and multiple headings are present within most cost categories. Headings include: travel, accommodation, accommodation and meals, equipment cost, communication costs, staffing costs, administration, cost of time, personal costs, costs at hospital, overall costs, project establishment costs, and hospital/care costs.

### Cost Category

- **Heading**
  - ⇒ Example
  - ⇒ Example

**Table 8. Headings within each Cost Category—Fixed, Variable, Direct, Indirect, Marginal, and General: Costs *Included* in Articles**

<u>Fixed Costs</u>	<u>Variable Costs</u>
<ul style="list-style-type: none"><li>• <u>Travel</u><ul style="list-style-type: none"><li>⇒ travel costs</li><li>⇒ travel time costs</li></ul></li><li>• <u>Equipment</u><ul style="list-style-type: none"><li>⇒ equipment (depreciated over 4 years)</li><li>⇒ installation (depreciated over 4 years)</li><li>⇒ equipment and depreciation costs</li><li>⇒ equipment costs</li><li>⇒ equipment maintenance costs</li><li>⇒ actual equipment</li><li>⇒ cost of teleconferencing system included capital investment costs subject to depreciation over 5 years</li><li>⇒ machinery</li><li>⇒ software</li></ul></li></ul>	<ul style="list-style-type: none"><li>• <u>Travel</u><ul style="list-style-type: none"><li>⇒ estimate of participants' travel costs</li><li>⇒ patient travel</li></ul></li><li>• <u>Equipment</u><ul style="list-style-type: none"><li>⇒ equipment cost</li><li>⇒ rental</li><li>⇒ service charges</li></ul></li><li>• <u>Communication</u><ul style="list-style-type: none"><li>⇒ long distance connection</li><li>⇒ data transmission costs</li><li>⇒ telecommunications costs</li><li>⇒ call costs</li></ul></li><li>• <u>Staffing</u><ul style="list-style-type: none"><li>⇒ psychiatrist (one hour)</li><li>⇒ fees for service</li><li>⇒ some salaries and wages</li><li>⇒ hospital personnel costs</li></ul></li></ul>

<sup>4</sup> The terms recorded here are taken from papers reviewed.



<ul style="list-style-type: none"> <li>• <u>Communication</u> <ul style="list-style-type: none"> <li>⇒ annual line charge</li> <li>⇒ rental cost of communications network</li> <li>⇒ communication cost using ISDN</li> <li>⇒ monthly rental cost of network</li> <li>⇒ ISDN line installation and line rental cost</li> <li>⇒ networking</li> </ul> </li> <li>• <u>Staffing</u> <ul style="list-style-type: none"> <li>⇒ some salaries and wages</li> <li>⇒ salaries and wages</li> <li>⇒ salaries and overheads</li> </ul> </li> <li>• <u>Administrative</u> <ul style="list-style-type: none"> <li>⇒ some administrative expenses of the hospital/center</li> <li>⇒ administrative expenses</li> </ul> </li> <li>• <u>Accommodation</u> <ul style="list-style-type: none"> <li>⇒ allowance for board</li> <li>⇒ accommodation</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>⇒ cost of a specialist</li> <li>⇒ cost of a GP</li> <li>• <u>Administrative</u> <ul style="list-style-type: none"> <li>⇒ cost of the paperwork</li> <li>⇒ supplies</li> </ul> </li> <li>• <u>Other</u> <ul style="list-style-type: none"> <li>⇒ other expenses</li> <li>⇒ drugs</li> <li>⇒ material expenses</li> </ul> </li> <li>• <u>Cost of Time</u> <ul style="list-style-type: none"> <li>⇒ staff time at sites</li> <li>⇒ estimate of participants' time</li> <li>⇒ cost of clinician time</li> <li>⇒ cost of patient time</li> </ul> </li> </ul>
<p style="text-align: center;"><b><u>Direct Costs</u></b></p> <ul style="list-style-type: none"> <li>• <u>Travel</u> <ul style="list-style-type: none"> <li>⇒ travel costs</li> <li>⇒ transport</li> </ul> </li> <li>• <u>Equipment</u> <ul style="list-style-type: none"> <li>⇒ internal and external service charges</li> <li>⇒ material expenses and rental</li> <li>⇒ equipment costs</li> </ul> </li> <li>• <u>Communication</u> <ul style="list-style-type: none"> <li>⇒ cell phone usage</li> <li>⇒ telecommunication services</li> <li>⇒ investment costs of equipment and line charges</li> </ul> </li> <li>• <u>Staffing</u> <ul style="list-style-type: none"> <li>⇒ training</li> <li>⇒ personnel</li> <li>⇒ nurse team services</li> <li>⇒ medical services</li> <li>⇒ payroll benefits</li> <li>⇒ physician visits</li> </ul> </li> <li>• <u>Administrative</u> <ul style="list-style-type: none"> <li>⇒ space</li> <li>⇒ supplies</li> <li>⇒ administrative overhead</li> </ul> </li> <li>• <u>Personal Costs</u> <ul style="list-style-type: none"> <li>⇒ personal costs</li> <li>⇒ costs of arranging home help</li> <li>⇒ time</li> <li>⇒ child care</li> <li>⇒ lost working hours</li> </ul> </li> <li>• <u>Costs at Hospital</u> <ul style="list-style-type: none"> <li>⇒ emergency department visits</li> </ul> </li> </ul>	<p style="text-align: center;"><b><u>Indirect Costs</u></b></p> <ul style="list-style-type: none"> <li>• Turning to relatives or friends for help</li> </ul>

<ul style="list-style-type: none"> <li>⇒ inpatient treatment</li> <li>⇒ laboratory and radiology charges</li> <li>⇒ pharmacy services</li> <li>⇒ laboratory</li> <li>⇒ treatment costs (divided into costs derived from medical doctors and nurse team support, costs linked to palliative therapy or chemo)</li> <li>• <u>Other</u> <ul style="list-style-type: none"> <li>⇒ other expenses</li> </ul> </li> </ul>	
<b>General Costs Included</b>	
<ul style="list-style-type: none"> <li>• <u>Travel</u> <ul style="list-style-type: none"> <li>⇒ airfare</li> <li>⇒ travel costs</li> <li>⇒ consultant transportation costs</li> <li>⇒ costs of traveling by different modes of transportation considered</li> <li>⇒ changes in transportation costs</li> <li>⇒ cost of traveling to hospitals for ftf: care mileage allowance, distance traveled, time spent traveling</li> <li>⇒ patient non-emergency transportation costs</li> </ul> </li> <li>• <u>Equipment</u> <ul style="list-style-type: none"> <li>⇒ equipment lease costs</li> <li>⇒ equipment costs</li> <li>⇒ maintenance costs: maintenance charges for equipment, should be calculated at 10-15%/ yr of the capital cost of equipment; include travel times and cost of maintenance provider</li> <li>⇒ initial purchase of hardware</li> <li>⇒ installation and maintenance</li> <li>⇒ hardware</li> <li>⇒ software</li> <li>⇒ costs of implementation of telehomecare system</li> <li>⇒ system costs</li> <li>⇒ operational expenses</li> <li>⇒ costs of each workstation</li> <li>⇒ home foetal monitoring equipment costs</li> </ul> </li> <li>• <u>Communication</u> <ul style="list-style-type: none"> <li>⇒ telecommunication costs</li> <li>⇒ line rental and call charges</li> <li>⇒ long distance telecommunication charges</li> <li>⇒ telecommunications and utilization charges</li> <li>⇒ monthly communication line charges</li> <li>⇒ running costs, e.g. phone line</li> <li>⇒ line charges</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <u>Cost of Time</u> <ul style="list-style-type: none"> <li>⇒ consultant's time</li> <li>⇒ midwife time</li> <li>⇒ time devoted by doctor/nurse team</li> <li>⇒ patient time</li> <li>⇒ physician time</li> <li>⇒ time for work stoppage for patients</li> <li>⇒ time spent on project for personnel</li> <li>⇒ average cost of consultant time for teledermatology and for conventional consultation</li> <li>⇒ average cost of GP time at a teledermatology consultation</li> </ul> </li> <li>• <u>Hospital/Care Costs</u> <ul style="list-style-type: none"> <li>⇒ number of referrals</li> <li>⇒ treatment costs</li> <li>⇒ standard ancillary care costs (e.g. laboratory services, ambulance)</li> <li>⇒ standard hospital costs (e.g. inpatient costs)</li> <li>⇒ daily costs per patient</li> <li>⇒ antenatal clinic visits</li> <li>⇒ antenatal inpatient days</li> <li>⇒ total cost of domiciliary care</li> <li>⇒ costs should incorporate any savings and expenditures in treating a patient in the course of the condition</li> <li>⇒ changes in the productivity of health care professionals</li> <li>⇒ costs per patient visit</li> <li>⇒ costs of ftf depend on length of clinic session, number of investigations, and number of reviews</li> <li>⇒ prescription costs considered</li> </ul> </li> <li>• <u>Administrative</u> <ul style="list-style-type: none"> <li>⇒ overhead costs</li> <li>⇒ facility charges</li> <li>⇒ supplies</li> <li>⇒ administration charges</li> <li>⇒ other project specific costs</li> <li>⇒ administrative overhead</li> </ul> </li> </ul>

<ul style="list-style-type: none"> <li>⇒ phone calls</li> <li>⇒ modem costs</li> <li>⇒ costs of telecommunication using ISDN lines</li> <li>⇒ installation costs for digital phone lines</li> </ul> <ul style="list-style-type: none"> <li>• <u>Staffing</u> <ul style="list-style-type: none"> <li>⇒ personnel for start-up and maintenance of the system</li> <li>⇒ employment costs of a consultant</li> <li>⇒ staffing costs</li> <li>⇒ consultant and support staff fees/wages</li> <li>⇒ RN costs, e.g. labour and benefits</li> <li>⇒ personnel costs</li> <li>⇒ hourly rate of consultant dermatologist and neurologist</li> <li>⇒ hourly rate of GP</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <u>Accommodation and Meals</u> <ul style="list-style-type: none"> <li>⇒ accommodation</li> <li>⇒ meals</li> </ul> </li> <li>• <u>Other cost considerations</u> <ul style="list-style-type: none"> <li>⇒ emerging and evolving reliability of technology</li> <li>⇒ skill level of end users</li> <li>⇒ uncertainty regarding the most efficient and effective applications</li> </ul> </li> <li>• <u>Project Establishment Costs</u> <ul style="list-style-type: none"> <li>⇒ preparation of submissions for funding approval</li> <li>⇒ recruitment of staff</li> <li>⇒ selection process to decide which projects are to proceed</li> <li>⇒ feasibility studies</li> <li>⇒ preparation of tenders for equipment</li> </ul> </li> </ul>
<p style="text-align: center;"><b><u>Marginal Costs</u></b></p> <ul style="list-style-type: none"> <li>• <u>Travel</u> <ul style="list-style-type: none"> <li>⇒ Patient travel</li> </ul> </li> <li>• <u>Staffing</u> <ul style="list-style-type: none"> <li>⇒ Physician fee</li> <li>⇒ Technician</li> <li>⇒ Lost work hours</li> </ul> </li> <li>• <u>Communication</u> <ul style="list-style-type: none"> <li>⇒ Telecommunications costs</li> </ul> </li> </ul>	

<b>Table 9. Fixed Costs, Variable Costs, Direct Costs, Indirect Costs, Marginal, and General Costs Excluded: Costs <i>Excluded</i> in Articles</b>	
<p style="text-align: center;"><b><u>Fixed Costs</u></b></p> <ul style="list-style-type: none"> <li>• None reported</li> </ul>	<p style="text-align: center;"><b><u>Variable Costs</u></b></p> <ul style="list-style-type: none"> <li>• <u>Equipment</u> <ul style="list-style-type: none"> <li>⇒ Equipment maintenance</li> </ul> </li> <li>• <u>Communications</u> <ul style="list-style-type: none"> <li>⇒ Telecommunications</li> </ul> </li> <li>• <u>Staffing</u> <ul style="list-style-type: none"> <li>⇒ Training</li> <li>⇒ Unproductive staff travel time</li> </ul> </li> </ul>
<p style="text-align: center;"><b><u>Direct Costs</u></b></p> <ul style="list-style-type: none"> <li>• None reported</li> </ul>	<p style="text-align: center;"><b><u>Indirect Costs</u></b></p> <ul style="list-style-type: none"> <li>⇒ Staff and physician costs</li> <li>⇒ Consultation fees</li> </ul>
<p style="text-align: center;"><b><u>General Costs Excluded</u></b></p> <ul style="list-style-type: none"> <li>• <u>Travel</u> <ul style="list-style-type: none"> <li>⇒ Research registrar's travel expenses</li> </ul> </li> <li>• <u>Equipment</u> <ul style="list-style-type: none"> <li>⇒ Annual maintenance costs</li> <li>⇒ Purchase of TM v/c equipment</li> <li>⇒ Equipment maintenance and repair</li> </ul> </li> <li>• <u>Communication</u></li> </ul>	<p style="text-align: center;"><b><u>Marginal Costs</u></b></p> <ul style="list-style-type: none"> <li>• None reported</li> </ul>

<ul style="list-style-type: none"> <li>⇒ ISDN line installation and rental</li> <li>• <u>Staffing</u> <ul style="list-style-type: none"> <li>⇒ Training staff to use equipment</li> <li>⇒ Enhanced GP job satisfaction</li> </ul> </li> <li>• <u>Psycho/social Costs on Patient</u> <ul style="list-style-type: none"> <li>⇒ Physical, social, psychological impact on patient of the skin complaint being resolved sooner rather than later</li> <li>⇒ Effect of long waiting lists for a specialist appointment on patient morale and patient health</li> <li>⇒ Convenience to patients of being seen at their local health centre</li> </ul> </li> <li>• <u>Patient Costs</u> <ul style="list-style-type: none"> <li>⇒ Less time off work</li> <li>⇒ Avoidance of paying for interim treatments while waiting for specialist appointment</li> <li>⇒ Costs of return visits</li> <li>⇒ Loss of income from missing work</li> <li>⇒ Costs for child care</li> <li>⇒ Primary cost savings due to avoided medical services i.e. hospitalization</li> </ul> </li> <li>• <u>Education</u> <ul style="list-style-type: none"> <li>⇒ Education experience for junior doctor</li> </ul> </li> </ul>	
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#### **6.4.4 Conclusion**

There is certainly no shortage of information regarding the cost of telemedicine. Specifically, there are more concrete definitions in this category than all of the others combined, although none are widely accepted or consistently used within the telehealth community. There were 27 articles that discussed, or conducted, at least one type of 'economic evaluation', but cost effectiveness analysis was noted more times than all other types of analysis.

In comparison to quality, access, and acceptability, it is most apparent with respect to the outcome category 'cost' that perspective must be identified. For example, in none of the other categories is the importance noted of identifying whose perspective is taken (e.g. societal versus healthcare system versus patient). Despite this, it was seldom, in terms of quantifiable numbers, that the specific perspectives of society, patient, provider, facility, or system was identified, or included, when doing an economic analysis. (It is interesting to note, however, that perspective becomes most identifiably important when money is involved).

In an effort to understand or predict costs under different conditions, some articles detail sensitivity or break-even analyses. Additionally, fixed, variable, direct, indirect, marginal, and general costs are commonly discussed in terms of what costs were included (or excluded) in an economic evaluation. Again, there is no apparent consistency in the application of these terms. It is obvious that many of the costs overlap, and it appears unclear as to which costs should be included in which categories or under which headings.

## 7. Discussion

### 7.1 Summary Points

The following points are taken from all aspects of the information document. This section is intended to list summary points that are the central aspects of this document.

- The overall objectives of this project are to *identify* and *define* nationally accepted sets of outcome indicators that can be accepted by the broader telehealth community when comparing or performing evaluations of various telehealth applications.
- The outcome guidelines generated throughout the course of this project are intended to become sets of agreed upon voluntary principles, not regulations.
- Perspective is important, and a crucial requirement in standardising outcome indicators will be to clearly define each one.
- Primary and secondary definitions were identified in the literature on the outcome indicators of quality, access, acceptability, and cost. It is with these definitions that the process and development of a consensus might begin.
- The literature revealed the use of some specific tools, particularly for the outcome indicators quality and acceptability. Consideration should be given to identifying such tools as 'recommended'.
- The aspects of quality measured included quality effects, various needs assessments, confidentiality, and the value of telemedicine.
- Access is a multidimensional concept representing the ease with which health services are initiated and sustained, and the conceptual domains of affordability, availability, and service diversity.
- The aspects of satisfaction measured included professional-patient interaction, comfort, feelings and experiences, technology, and the preference between face-to-face and telehealth.
- A little over half of the articles abstracted noted cost information. Several economic evaluation methods were defined, along with other costs associated with telemedicine, but no single economic evaluation model has yet been accepted.

### 7.2 Learning From, and Aligning With, Other Activities

In order to apply 'common' healthcare tools to the telehealth arena, there is a need to use existing tools and definitions as far as possible. Modification of existing tools and definitions, or development of new ones, should be pursued only when essential. This approach would align telehealth with other healthcare disciplines and associated outcome activities, avoid duplication of effort, and retain some integrity for the definitions and tools adopted. Appendix A outlines other health and e-health outcomes initiatives.

One example of an opportunity to align is in the use of scales. Scales for satisfaction surveys in the telehealth literature have been shown to use a wide variety of descriptors. One consideration would be to adopt the Statistics Canada definition and scale for 'Health Satisfaction, Self-Assessed'. This parameter is defined as "the perception of a person of his or her satisfaction with his or her health status or condition". The Likert-like scale used to measure this includes six levels: Very Satisfied, Generally Satisfied, Somewhat Satisfied, Somewhat Dissatisfied, Generally Dissatisfied, and Very Dissatisfied. The data can then be collapsed into two categories of Satisfied and Dissatisfied for reporting. Adoption of this definition and scale would be simple and convenient.

Similar approaches (i.e. adoption of existing definitions) could be adopted for other variables used by Statistics and Health Canada. For example, each of the following parameters has been defined and could have relevance to telehealth: Age; Age By Life Cycle Groupings; Commuting Distance; Contact with health professionals; Geographic Code; Health problems, self-reported; Health status, self-assessed; May not require hospitalization; Population Density; Postal Code; Province or Territory; Rural Area (RA); Total Years of Schooling; Urban Area (UA); Urban Population Size Group

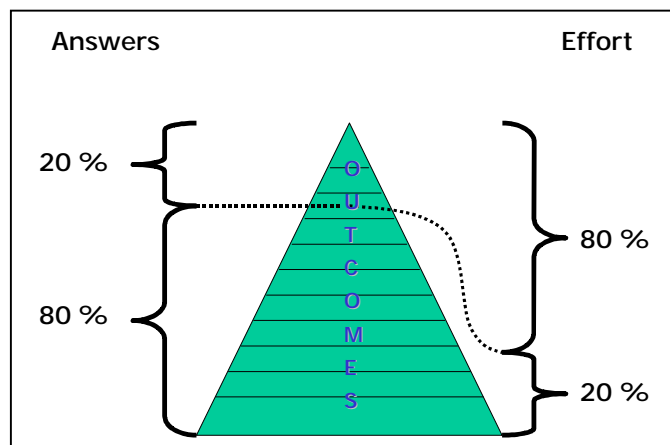
Aligning telehealth definitions with existing ones has an additional advantage. It might become possible to combine data from different groups (not merely different studies) to permit additional analysis. Consider also the potential that would arise if telehealth data collected during studies was routinely “geo-encoded”.

### 7.3 A Draft Conceptual Telehealth Outcomes Development (TOD) Model

We propose that in order to move this area forward in an orderly and efficient manner, there is value in developing a conceptual model that offers a *structured process for outcomes development*.

As a prelude to this proposed model, two principles are suggested as being essential for future discussions.

- *Principle of Compromise.* Common ground can be found when there is a focus on the goal and a mutual desire to attain it. Satisfying all ‘needs’ is impossible, but progress can be made on identifying and defining a limited number of common indicators and measures if participants are willing to compromise. The ISO struggles with this same issue (<http://www.iso.ch/iso/en/commcentre/isobulletin/comment/2003/April2003.html>)
- *Pareto Principle.* (Sometimes referred to as the 80/20 rule). It should be possible to **answer 80%** of the questions we ask in regard to the ‘value’ of telehealth by focussing **20% of our effort** on identifying key telehealth / e-health outcome indicators. The remaining 20% of answers can only be found by expending an additional 80% of effort, which is inefficient, has a poor ROI (Return On Investment), and is most likely unnecessary in the larger scheme (Figure 1).

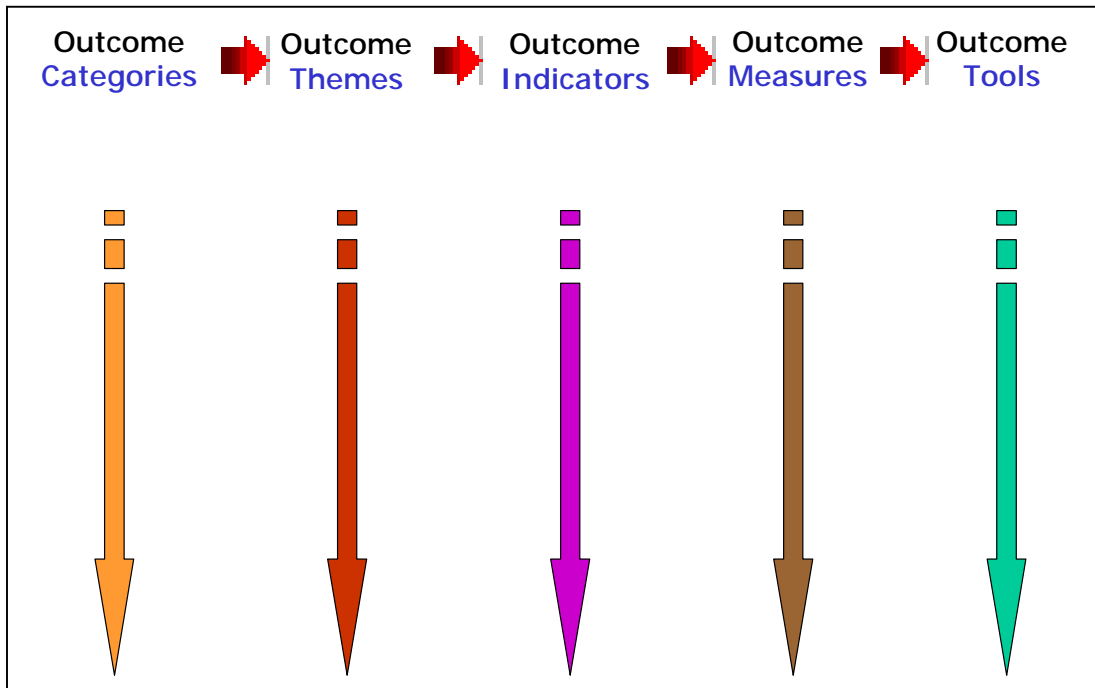


**Figure 1. Illustration of the Pareto Principle or 80/20 rule.**

The model is at an early stage of development, and input is sought to refine it to a point that it can be applied in practice. Below a conceptual draft of the Telehealth Outcomes Development (TOD) model is presented for consideration and debate.

### 7.3.1 Outline

There are five domains to the draft TOD model: category, theme, indicator, measure, and tool. It should be possible to identify specific and definable elements to populate each domain (Figure 2).



**Figure 2. Five Domains of the Telehealth Outcomes Development (TOD) Model**

- 'Outcome Category' is the overarching domain within which the intent is to identify a discrete series of areas of healthcare focus. At this time it is ill defined, but possible examples would include:

*Health Status; Health Resources; Health Services Utilisation; Non-Health Determinants.*

- 'Outcome Theme' has relied upon the IOM model to describe essential areas of focus for evaluation:

*Quality, Access, Acceptability, and Cost.*

- 'Outcome Indicator' is applied as defined earlier in this document: *The parameter it is desired to assess in order to determine if a 'tele' or 'e-related' intervention has had a result or visible effect.* Examples might include:

*Quality of Life; Quality of Care; Timeliness; Availability.*

- 'Outcome Measure' is also applied as defined earlier in this document: *The specific measure used to quantify (quantitative measure) or gauge (qualitative measure) the result or visible effect of a 'tele' or 'e-related' intervention.* Examples might include:

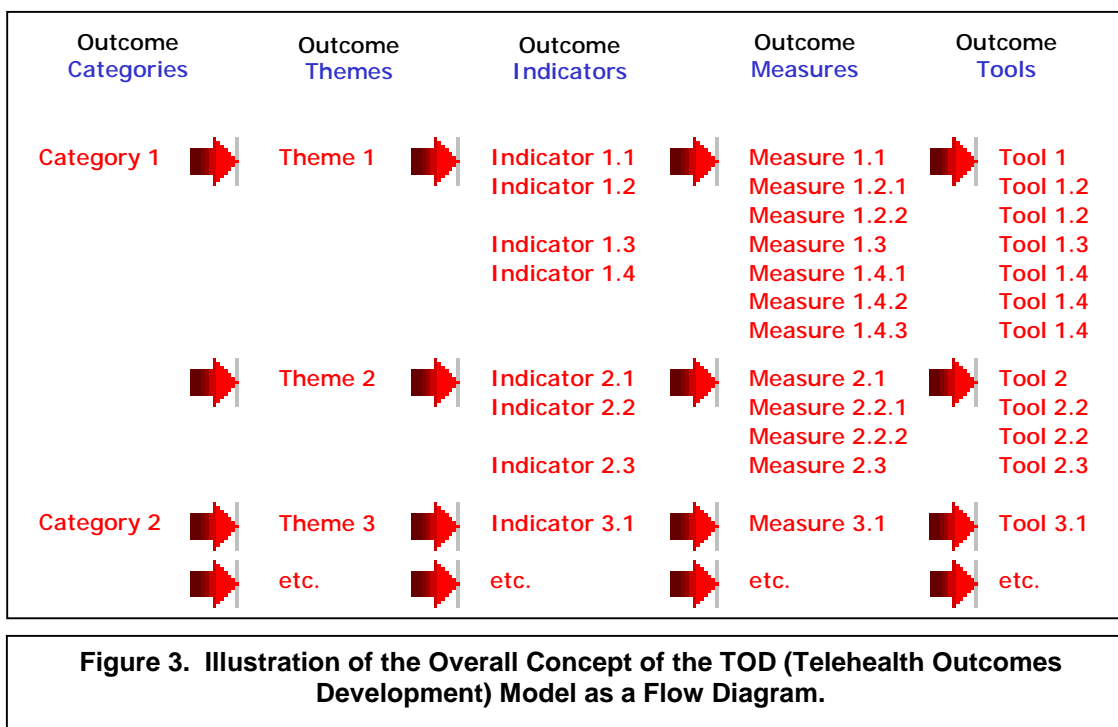
Morbidity, Number of Hospitalisations; Length of Stay; Distance to Nearest Facility; Rurality.

- Similarly, 'Outcome Tool' is applied as defined earlier in this document: *The specific instrument used to collect quantitative or qualitative data for any single outcome measure.* Here, an example might include:

SF-36, SF-12, or the SF-8 instruments (reliable and validated tools used to measure quality of life in each of eight health domains).

Within any 'Outcome Category' a discrete number of 'Outcome Themes' would be identified. Similarly, within each theme several 'Outcome Indicators' could be described. For each outcome indicator, one or more specific 'Outcome Measures' should be identifiable, and finally, for each outcome measure, there will be the need for some form of tool with which to capture the data for analysis.

Capturing this visually, the overall TOD concept would appear as seen in Figure 3 below.



To provide some perspective and illustrate the concept, the following series of Tables 10 - 13 and Figures 4 – 7 show what the TOD Model might look like using examples of potential Outcome Themes, Indicators, Measures, and Tools. These examples are merely suggestions made in an effort to stimulate thought and discussion regarding the possible development of the TOD model.



## QUALITY

Outcome Theme	Outcome Indicator	Outcome Measure
Quality	Quality of Life	8 domains of Quality of Life: <ul style="list-style-type: none"> <li>• limitations in physical activities because of health problems</li> <li>• limitations in usual role activities because of physical health problems</li> <li>• bodily pain</li> <li>• general health perceptions</li> <li>• vitality (energy and fatigue)</li> <li>• limitations in social activities because of physical or emotional problems</li> <li>• limitations in usual role activities because of emotional problems</li> <li>• mental health (psychological distress and well-being)</li> </ul>
	Health Status	<ul style="list-style-type: none"> <li>• Changes in morbidity</li> <li>• Population perspective on changes to health status i.e. client assessment</li> </ul>

**Table 10. Illustrative Examples of Potential Outcome Indicators and Measures for the Outcome Theme of Quality.**

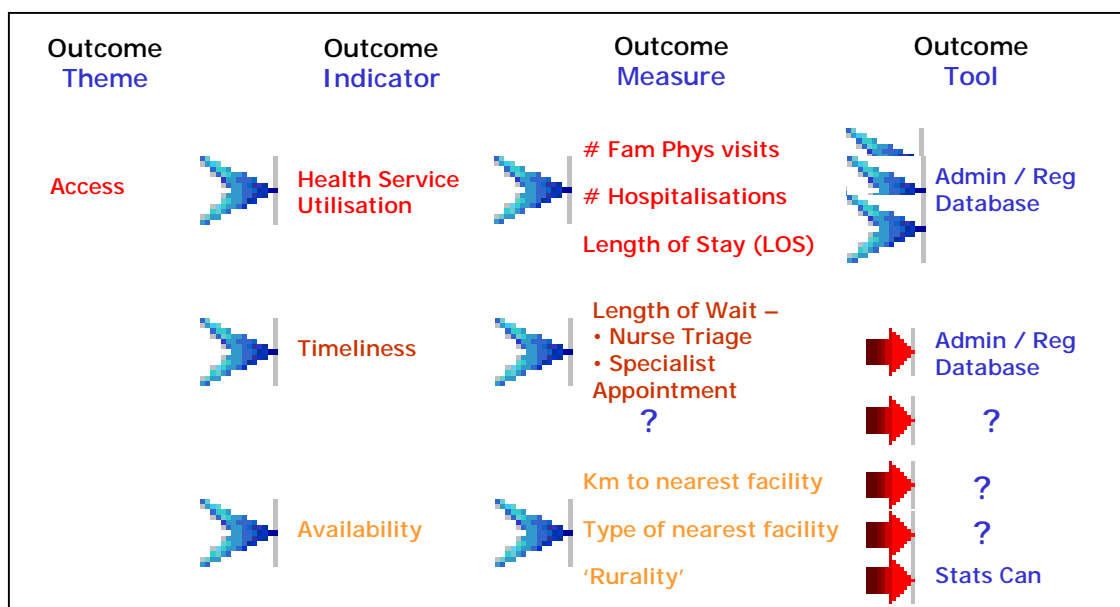
Outcome Theme	Outcome Indicator	Outcome Measure	Outcome Tool
Quality	Quality of Life - Individual	Vitality Limitations - Physical Mental Health	SF-36 or SF-12 or SF-8
	Health Status - Population	Morbidity ?	Admin / Reg Database ?
	Quality of Care	Length of Stay (LOS) ?	Admin Database ?

**Figure 4. Flow Diagram Illustration of Examples of Potential Outcome Indicators and Measures for the Outcome Theme of Quality.**

## ACCESS

Outcome Theme	Outcome Indicator	Outcome Measure
Access	Utilization of Health Care Services	<ul style="list-style-type: none"> <li>• Length of hospital stay</li> <li>• Number of emergency visits</li> <li>• Number of hospitalizations</li> <li>• Number of physician visits</li> </ul>
	Timeliness of Care—this is most easily identified as relevant to the clinical setting	<ul style="list-style-type: none"> <li>• Length of wait to see a health care worker</li> <li>• Length of wait for specialist care i.e. MRI</li> </ul>
	Availability	<ul style="list-style-type: none"> <li>• Number of kilometres to nearest health care facility</li> <li>• Rural vs. urban and distance to nearest health care facility in each setting</li> <li>• Category of nearest facility—hospital or clinic; primary, secondary, or tertiary care</li> </ul>

**Table 11. Illustrative Examples of Potential Outcome Indicators and Measures for the Outcome Theme of Access.**

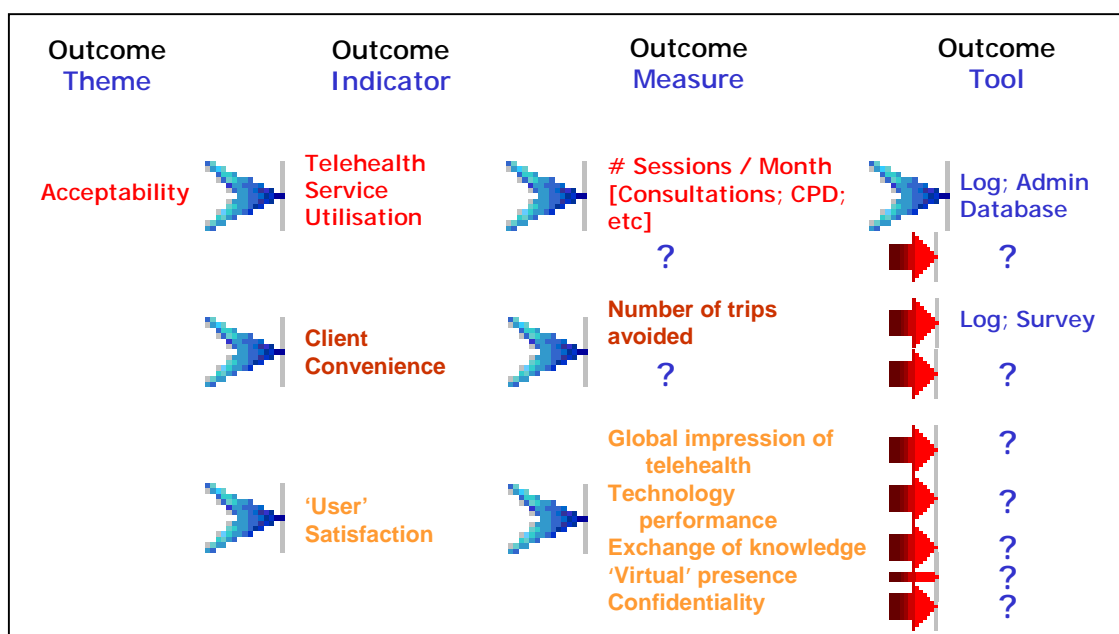


**Figure 5. Flow Diagram Illustration of Examples of Potential Outcome Indicators and Measures for the Outcome Theme of Access.**

## ACCEPTABILITY (SATISFACTION)

Outcome Theme	Outcome Indicator	Outcome Measure
Acceptability	Rate of Use	Clinical - # consults / month Research - # meetings / mth Education – # sessions / mth Administration - meetings / mth Mixed – Total # events / mth
	Convenience	Number of trips avoided
	Client satisfaction	Considering the articles by both Williams et al. (2001) and Agrell et al. (2001), we propose identifying 5 measures: 1. Global impressions of telehealth 2. Technological performance 3. Exchange of knowledge 4. Physical presence 5. Confidentiality

**Table 12. Illustrative Examples of Potential Outcome Indicators and Measures for the Outcome Theme of Acceptability.**

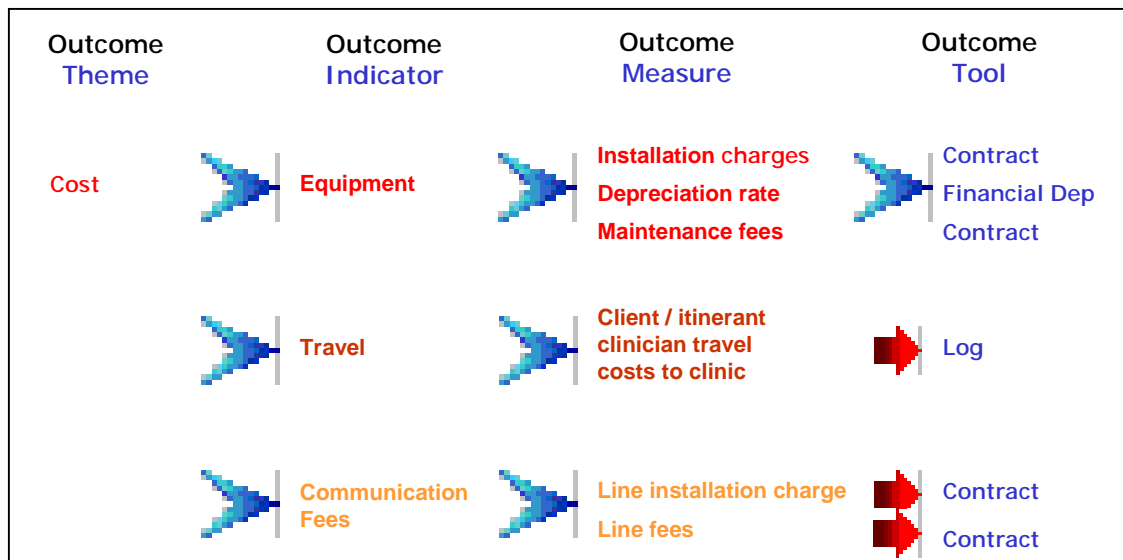


**Figure 6. Flow Diagram Illustration of Examples of Potential Outcome Indicators, Measures, and Tools for the Outcome Theme of Acceptability.**

## COST

Outcome Theme	Outcome Indicator	Outcome Measure
Cost	Equipment	<ul style="list-style-type: none"> <li>• Installation</li> <li>• Equipment and depreciation costs</li> <li>• Software</li> <li>• Service charge</li> <li>• Maintenance costs</li> </ul>
	Patient / Itinerant Clinician travel	<ul style="list-style-type: none"> <li>• Average cost per trip to health care centre</li> </ul>
	Communication	<ul style="list-style-type: none"> <li>• Line fees</li> <li>• ISDN line installation</li> <li>• Networking</li> <li>• Long distance connection</li> <li>• Data transmission costs</li> <li>• Cell phone usage</li> <li>• Modem costs</li> </ul>
	Administrative	<ul style="list-style-type: none"> <li>• Administrative expenses</li> <li>• Supplies</li> </ul>
	Staffing	<ul style="list-style-type: none"> <li>• Salaries and wages</li> <li>• Fees for service</li> <li>• Hospital personnel costs</li> </ul>

**Table 13. Illustrative Examples of Potential Outcome Indicators and Measures for the Outcome Theme of Cost.**



**Figure 7. Flow Diagram Illustration of Examples of Potential Outcome Indicators, Measures, and Tools for the Outcome Theme of Cost.**

#### **7.4     *Taking The Second Step – A Workshop Proposal***

The first step in the process was research and development of this Information Document. The second step - a workshop - is now being organized. The intent is to gather a small group of interested individuals within Canada to further pursue the project. At the same time, it is anticipated the workshop will gauge the level of interest in a) developing a collective pan-Canadian agreement in principle to identify, define, and apply a core set of voluntary outcome indicators, and b) using the TOD model.

The stature (within the Canadian telehealth environment), collective expertise, and experience of workshop participants should enable consensus to be achieved around the value of the principle involved, and the conceptual model. It is anticipated that consensus will also be possible on identifying a discrete number of outcome indicators, measures, and potential tools that will form the basis for the third step.

Having identified these preliminary indicators, measures, and tools, the third step will be to clearly define each, and to share this material through the iterative Outcomes Document process described earlier. This would serve to gather broad input, as well as achieve broad dissemination and consensus.

## Answer Sheet: StatsCan Definitions for Selected Parameters

The answers to the exercise described on pages 27 and 28 are shown below. Some specific elements commonly missed have been underlined in the accepted StatsCan definitions. One common error is omitting reference to some denominator. Additional explanatory comments about the utility of the parameter have also been provided.

### 1. Population

**Definition:** The number of people living in a geographic area by age and sex.

**Comments:** A population's size and age/sex composition impact the health status of a region and its need for health services. Population data also provide the "denominators" used to calculate rates for most health and social indicators.

**Source:** Statistics Canada, Demography Division.

### 2. Urban Population

**Definition:** People living in urban areas. An urban area is defined as having a minimum population of 1,000 and a population density of 400 people per square kilometre.

**Comments:** This community characteristic allows users to compare regions with similar proportions of urban/rural population.

**Source:** Statistics Canada, 1996 Census.

### 3. Total Mortality

**Definition:** Crude count, crude rate and age-standardised rate of death from all causes (ICD-9 001-799, E800-E999) per 100,000 population.

**Comments:** Indicates the overall health of the population and is similar to what is measured by life expectancy. Age-standardisation (as opposed to crude rates) allows for comparisons between health regions, provinces, and countries.

**Sources:** Statistics Canada, Vital Statistics, Death Database, and Demography Division (population estimates).

### 4. Contact with Medical Doctors

**Definition:** Population aged 12 and over who have consulted with a medical doctor/paediatrician in the past 12 months.

**Comments:** 'Medical doctor' includes family or general practitioners as well as specialists such as surgeons, allergists, orthopaedists, gynaecologists, or psychiatrists.

**Sources:** Statistics Canada

## 5. Doctors

**Definition:** General practitioners (including uncertified specialists) or family practitioners (family medicine and emergency family medicine specialists) per 100,000 population on December 31st of the reference year. Specialist physicians (specialty based on most recent certified specialty) on December 31st of the reference year, per 100,000 population.

**Comments:** It can be seen this is a far more complex definition with some very specific provisos within the definition.

Physician to population ratios are used to support health human resource planning. Note that physician density ratios do not take into account workload or type of services provided. In some regions, health facilities and personnel provide services to a larger community than the residents of the immediate region. In others, residents may seek care from physicians and specialists *outside the region where they live*, which has significant implications for telehealth. The ratio of physicians to population reflects the number of doctors in a region and has not been adjusted to take these movements into account. The extent to which this affects individual regions is likely to vary.

**Source:** Canadian Institute for Health Information, Southam Medical Database.

## **SECTION 4**

### ***Appendices***



## Appendix A: Other Health and e-Health Outcomes Initiatives

These are intended to be broadly illustrative examples only; this Appendix does not constitute a detailed listing of outcomes related projects. Additional information on other projects may be found at the KUUC website - <http://kuuc.chair.ulaval.ca/english/index.php> - and searching for 'outcome indicators'.

### **A1 Canadian Activities**

#### **A1a) CIHI (Canadian Institute for Health Information)**

Two particular activities were identified for CIHI and both are a part of the larger 'Roadmap' initiative. Roadmap is a collaborative effort between the Canadian Institute for Health Information (CIHI), Statistics Canada, Health Canada and a number of key stakeholder groups, including provincial and territorial health ministries. The purpose is to meet priority health information requirements that serve to improve public health and the quality of Canada's health system.

I) CIHI has led the 'Comparable health and health system performance indicators for Canada, the provinces and territories' project. In September 2000, Canada's First Ministers issued a Communiqué on health in which they agreed to provide clear reporting to Canadians, beginning in September 2002. In response to this communiqué, common indicators have been developed for fourteen areas of health status, health outcomes and quality of health care services. Grouped into three categories, these indicators are:

- *Health Status*
  1. Life Expectancy
  2. Infant Mortality
  3. Low Birth Weight
  4. Self-reported Health
- *Health Outcomes*
  5. Change in Life Expectancy
  6. Improved Quality of Life
  7. Reduced Burden of Disease, Illness and Injury
- *Quality of Service*
  8. Waiting Times for Key Diagnostic and Treatment Services
  9. Patient Satisfaction
  10. Hospital Re-admissions for Selected Conditions
  11. Access to 24/7 First Contact Health Services
  12. Home and Community Care Services
  13. Public Health Surveillance and Protection
  14. Health Promotion and Disease Prevention

To achieve agreement on comparable reporting by all F/P/T jurisdictions in the 14 indicator areas, Health Ministers established a joint federal and provincial / territorial Performance Indicators Reporting Committee (PIRC).

II) CIHI is also working with key players across the country to develop specific national indicators in the following areas:

- continuing care
- drug utilisation

- home care
- mental health and addiction services
- rehabilitation services.

For example, CIHI has led the 'Development of National Indicators and Reports for Home Care' project, and in Phase 2 has presented Proposed Home Care Indicators. These cover specific items within defined 'Information Requirement' categories (*italicised below*), viz:

- *Health Conditions*
  - Health Status of Home Care Clients
- *Human Function*
  - Functional Status – ADLs and IADLs
  - Cognitive Status of Home Care Clients
  - Presence of Disruptive Behaviours
- *Personal Resources*
  - Availability of Informal Caregivers
  - Informal Caregiver Burden
- *Living Conditions*
  - Living Arrangements
  - Accommodation Setting
- *Accessibility*
  - Time Waiting for Home Care
  - Home Care Access Per Capita
- *Effectiveness*
  - Service Goals Met
  - Functional Outcomes
- *Utilisation*
  - Population Utilisation
  - Use of Emergent Care Services
  - Temporary Transfers to Short-term and/or Transitional Beds
- *Home Care Expenditures*
  - Per Capita Regional Expenses on Home Care.

#### **A1b) Saskatchewan Initiative**

In March 2000, Saskatchewan Health released the first in a series of health service and outcome indicators that have been developed in collaboration with the Health Services Utilization Research Commission (HSURC) and health districts. These assist the districts in their program planning and decision-making activities. The first release focuses on Mothers and Infants, and subsequent releases will focus on Children and Youth, Adults and Seniors.

[http://www.health.gov.sk.ca/ph\\_br\\_ae\\_health\\_soi.html](http://www.health.gov.sk.ca/ph_br_ae_health_soi.html)

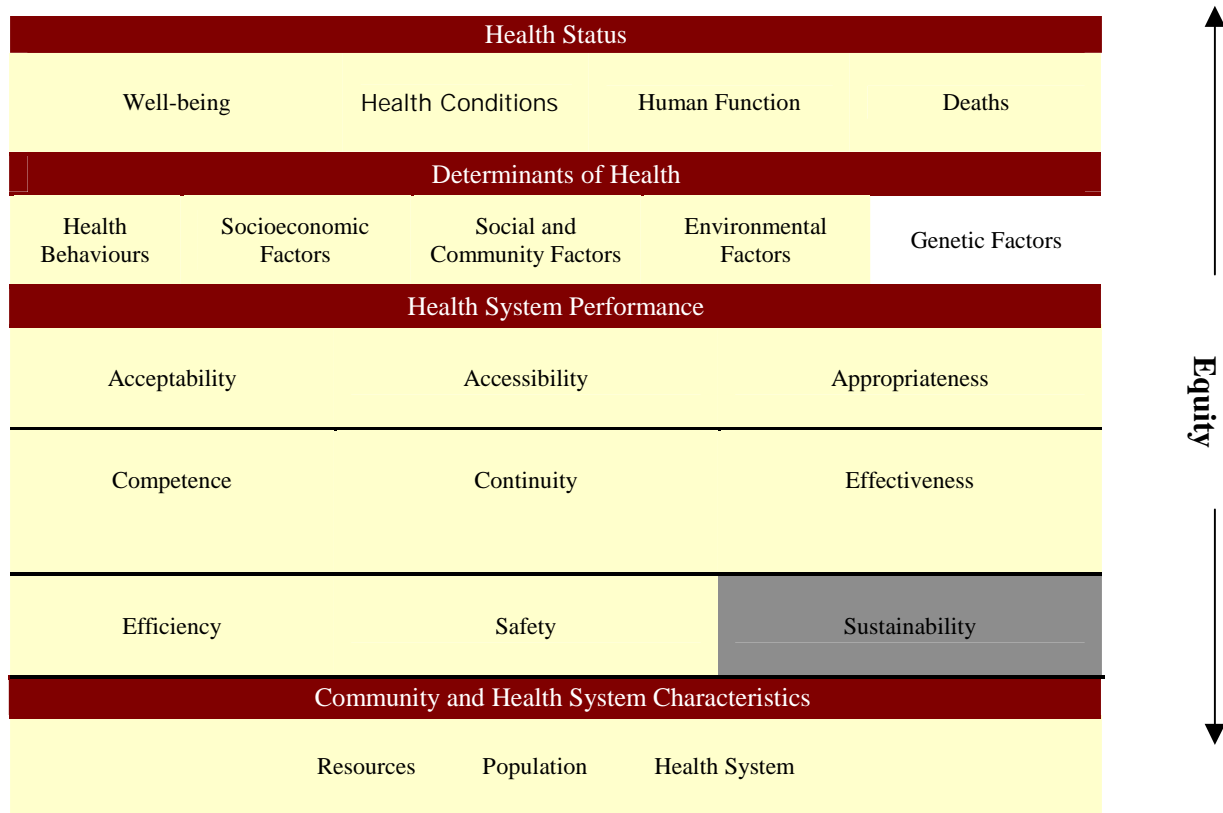
#### **A2) ISO (International Standards Organisation)**

ISO has initiated its 'Health Informatics — Health Indicators Conceptual Framework' project (ISO 2001). Presently, this is very much a higher level framework, and does not identify individual indicators or specific data elements for the health indicators conceptual framework. However, it has been proposed that a subsequent ISO work item will address the characteristics and common attributes of indicators contained in the health indicators conceptual framework, and their relationship to a health data model.

The framework (conceptualized in Figure A below):

- (a) Defines the appropriate dimensions and sub-dimensions that are required to describe the health of the population, and the performance of a health care system;
- (b) is sufficiently broad (high-level) to accommodate a variety of health care systems; and
- (c) is comprehensive, encapsulating all of the factors that are related to health outcomes and health system performance and utilisation, and regional and national variations.

**Figure A — ISO Health Indicators Conceptual Framework**



### **A3) OECD (Organisation for Economic Co-Operation and Development)**

OECD embarked on a three-year 'Health Project' in 2001. The project focuses on measuring and analysing the performance of health care systems in Member countries and factors affecting performance. The purpose of the analysis is to help decision-makers formulate evidence-based policies to improve their health systems' performance. Related to this project, OECD has several ongoing initiatives directed at the measurement of health and health system performance. Ongoing OECD initiatives have been described as tending to concentrate on specific health indicator definitions, data requirements, and data sources. Jee and Or (1999) suggest that the role of the OECD with respect to performance indicators encompasses the following elements:

- The identification of a common set of health outcome indicators

- Standardisation of concepts and data definitions
- Application of these standards in national data infrastructure
- Further analytical work using these data.

One specific activity is aimed at developing indicators for the technical quality of medical care, as one of the key dimensions of health systems performance.

#### **A4) EU / EC (European Union / European Community)**

The EU has initiated the European Community Health Indicators (ECHI) program, and prepared the report 'Design for a set of European community health indicators' (EU 2001). This report proposes a comprehensive list of health indicators, thus focusing on the core of the European Commission's Health Monitoring Programme: *'to contribute to the establishment of a Community health monitoring system'*. This concept is required to:

1. Measure health status, its determinants, and the trends therein throughout the Community;
2. Facilitate the planning, monitoring and evaluation of Community Programmes and actions, and
3. Provide Member States with appropriate health information to make comparisons and support their national health policies.

In the design of the indicator set, a set of explicit criteria was applied. These included:

- Be *comprehensive and coherent*, i.e. cover all domains of the public health field;
- Take *account of earlier work*, especially that by WHO-Europe, OECD and Eurostat;
- Cover the priority areas which Member States and Community Health Policies currently pursue.

The proposed indicators are, in most cases, defined as generic indicators, i.e., their actual operational definitions have not yet been attempted. This is the next anticipated stage. Currently the following categories have been identified:

- 1 Demographic and Socio-economic Factors**
  - 1.1 Population
  - 1.2 Socio-economic factors
- 2 Health Status**
  - 2.1 Mortality
  - 2.2 Morbidity, disease-specific
  - 2.3 Generic health status
  - 2.4 Composite health status measures
- 3 Determinants of Health**
  - 3.1 Personal and biological factors
  - 3.2 Health behaviours
  - 3.3 Living and working conditions
- 4 Health Systems**
  - 4.1 Prevention, health protection and health promotion
  - 4.2 Health care resources
  - 4.3 Health care utilisation
  - 4.4 Health expenditures and financing
  - 4.5 Health care quality/performance

Within the four major classes and sub-classes, greater detail as to specific indicators was provided (see EU, 2001).

#### **A5)      *Australia***

In March 1994 Australian Health Ministers agreed to the development of nationally consistent benchmarks for the health sector in a number of areas. Ministers also agreed to the establishment of a working group of Commonwealth, State and Territory officers to coordinate the development of the benchmarks. This group, known as the National Health Ministers' Benchmarking Working Group (NHMBWG), first met in August 1994. As a result, the National Hospital Outcomes Program (NHOP) was developed (AIHW, 1996).

The program has established national indicators of performance in the health sector under the following categories:

- quality
- production efficiency
- outcomes
- investment utilisation
- access
- human resource management, and
- business operations.

In establishing indicators this group was asked to give due consideration to the validity of the indicators (in terms of the degree to which they provided clear and direct information about the efficiency and effectiveness of the health sector); the 'understandability' of the indicators; and the ease and cost of the collection of the relevant data. They were also required to develop standardised definitions of the nominated performance indicators, to ensure comparability of data across all States/Territories. Since identifying the indicators, an annual report of progress is prepared.

#### **A6)      *Australia and New Zealand***

The previously mentioned ANZTC initiative is described here in detail, since many of the fundamental approaches or indicators may be appropriate for consideration within this project. The first Table shows the ANZTC Telehealth Data Definitions Summary for the 31 items identified. The second series of Tables provide full details for each item – the Telehealth Data Definitions.

## Table 8. ANZTC Telehealth Data Definitions Summary

Data items correspond to each of five entities

Taken from: [http://www.telehealth.org.au/discussion\\_papers/datadef/summary.htm](http://www.telehealth.org.au/discussion_papers/datadef/summary.htm)

Entity	Telehealth facility	Telehealth session	Client	Healthcare worker	Telehealth service
Data Items	<i>All Telehealth Activities</i>		<i>Clinical Care Only</i>		
	Identifier (code or name)	Identifier	Identifier*	Job category	Clinical care activity
	Setting	Date of session	Date of referral	Employment basis	Urgency
	Location*	Start time	Time of referral		Service classification
		End time	Sex*		Participant type
		Other sites connected	Date of birth*		Participant count
		Purpose of session	Indigenous status*		Duration of clinical care activity
		Telehealth equipment	Usual residence*		
		Peripheral devices	Presenting problem		
		Telecommunications type			
		Bandwidth			
		Operational problems			
	* indicates data definition drawn from NHDD				

**Table 9. Telehealth Data Definitions**

**Table 9.1 - TELEHEALTH FACILITY**

Facility at which telehealth session is conducted.

**ITEM:**                      **Telehealth Facility Identifier (if available)**

**Definition:** Code which uniquely identifies a facility within a healthcare system.

**Context:** Telehealth. Indicates where telehealth activity is conducted.

**Guide for use:** Sessions conducted in the settings of 'home' or 'general practice' or 'specialist office' will not have a facility number and therefore this data item should be left blank.

**Source:** nil

**ITEM:**                      **Telehealth Facility Name (if code not available)**

**Definition:** Name of facility at which the telehealth session is conducted.

**Context:** Telehealth. In the absence of a 'Telehealth facility identifier', this data item indicates where telehealth activity is conducted.

**Guide for use:** Recorded when facility identifier is not available.  
If the session is in a home, record "HOME".  
If the session is in a general practice, record the name of the practice.  
If a specialist's practice, record the name of the specialist.

**Source:** nil

**ITEM:**                      **Setting**

**Definition:** Type of facility at which a telehealth session is conducted.

**Context:** Telehealth. Helps track the diffusion of telehealth within and outside the public health system.

**Domain:**

1	hospital
2	community health centre
3	multi-purpose centre
4	general practice
5	specialist practice

- 6 home
- 8 other

**Guide for use:** Multi-Purpose Centres provide a collection of services, which are coordinated to meet the needs of rural and remote communities. MPC's serve as a base for a range of health and community based services such as hospital care, residential aged care (nursing home and hostel places), primary health care and paramedical services, and services for people able to live in the community with support.

**Source:** nil

**Comment:** This data item facilitates description of the type of facility at which telehealth is conducted.

**ITEM:**                    **Geographical Location of Establishment**

**Definition:** Geographical location of the establishment. For establishments of more than one geographical location, the location is defined as that of the main administrative centre.

**Data domain:** The geographical location is reported using a five digit numerical code to indicate the Statistical Local Area (SLA) within the reporting State or Territory, as defined in the Australian Standard Geographical Classification (Australian Bureau of Statistics, catalogue number 1216.0).

**Guide for use:** The Australian Standard Geographical Classification (ASGC) is updated on an annual basis with a date of effect of 1 July each year. Therefore, the edition effective for the data collection reference year should be used.  
The Australian Bureau of Statistics' National Localities Index (NLI) can be used to assign locality or address in Australia to a SLA. The NLI is a comprehensive list of localities in Australia with their full code (including SLA) from the main structure of the ASGC.  
For the majority of localities, the locality name (suburb or town, for example) is sufficient to assign an SLA. However, some localities have the same name. For most of these, limited additional information such as the postcode or State can be used with the locality name to assign the SLA.  
In addition, other localities cross one or more SLA boundaries and are referred to as split localities. For these, the more detailed information of the number and street of the establishment are used with the Street Sub-index of the NLI to assign the SLA.

**Source:** National Health Data Committee, 1999, *National Health Data Dictionary* Version 8.0 Australian Institute of Health & Welfare, Canberra.

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**Table 9.2 - TELEHEALTH SESSION**

A period of time set aside for health-related activities that involves the use of telecommunications technology to link two or more facilities. Such activities might include delivering services, providing professional and peer supervision, or educational and administrative interactions. A single telehealth session may be made up of one or several activities, which may or may not be recorded individually, and may be between:

- a client and a healthcare worker;
- a client, a healthcare worker, and another person such as an interpreter, another healthcare worker, or family member/carer;
- two or more healthcare workers; or
- people involved in educational and administrative interactions, which may or may not include healthcare workers.

It is worth noting that at this stage, and for the purpose of current data collection, technology refers to videoconferencing and image transfer modalities, and excludes the use of telephone, facsimile and email for data transfer.

**ITEM:**                      **Telehealth Session Identifier**

**Definition:** Unique identifier allocated to a single telehealth session.

**Context:** Telehealth. A session identifier is required to enable the linking of data from multiple sites involved in a telehealth session.

**Guide for use:** The 'Telehealth session identifier' will vary by jurisdiction. For example, in Queensland Health, where a centralised booking system exists for multipoint videoconferencing, the identifier will be the reference number allocated by CITEC. For point-to-point videoconferencing and image transfer, there may not be a unique identifier.

**Source:** nil

**ITEM:**                      **Date of Telehealth Session**

**Definition:** Date on which telehealth session commenced at a site.

**Context:** Telehealth. This data item will enable tracking of patterns of telehealth activity over time.

**Layout:** DDMMCCYY

**Source:** nil

**ITEM:**                      **Telehealth Session Start Time**

**Definition:** Time at which a telehealth session commenced at a site.

**Context:** Telehealth. Enables determination of session duration and hence calculation of costs associated with the telehealth session.

**Layout:** HH:MM

**Data Domain:** 24 hour clock – 0000 (midnight) to 2359

**Source:** nil

**ITEM:**                    **Telehealth Session End Time**

**Definition:** Time at which a telehealth session finished at a site.

**Context:** Telehealth. Enables determination of session duration and hence calculation of costs associated with the telehealth session.

**Layout:** HH:MM

**Data Domain:** 24 hour clock – 0000 (midnight) to 2359

**Source:** nil

**ITEM:**                    **Other Sites Connected**

**Definition:** Count of all other sites that were involved in the telehealth session while the site was connected to the session.

**Context:** Telehealth. Indicates the size of a multipoint connection.

**Guide for use:** Recorded by each telehealth site for all other sites.  
Note that there will be some anomalies in the number of sites recorded by each site due to sessions in which some participants drop in and out of the session.

**Source:** nil

**ITEM:**                    **Purpose of Telehealth Session**

**Definition:** The principal purpose or main reason for conducting a telehealth session.

**Context:** Telehealth. Enables description of general purpose for which telehealth is used.

**Domain:**

1	clinical care
2	education and/or training
3	management and/or administration
4	research and/or evaluation
5	health promotion and/or public health

8 other

**Guide for use:** Consulting or diagnostics should be recorded as domain item 1 "clinical care". Supervision, mentoring, continuing professional education and distance learning should be recorded as domain item 2 "education and training".

**Source:** nil

**ITEM:** **Telehealth Equipment**

**Definition:** Equipment utilised by a site in a telehealth session.

**Context:** Telehealth. Provides information that will enable costs associated with telehealth to be calculated.

**Domain:**

1	videoconference equipment - desktop system
2	videoconference equipment - set-top system
3	videoconference equipment - room-based system
4	teleradiology equipment
5	telepathology equipment
8	other

**Guide for use:** May be multi-valued.  
A desktop system is PC-based.  
A set-top system, sometimes called a compact system, is generally attached to a TV.  
A room-based system is a self-contained unit with 1 or 2 large monitors.

**Source:** nil

**Comment:** In current telehealth practice, videoconferencing systems and medical image transfer systems are the main types of equipment utilised.

**ITEM:** **Peripheral Devices Used**

**Definition:** Peripheral devices utilised at a site during a telehealth session.

**Context:** Telehealth. The use of peripheral devices has implications in terms of capital investment, and thus, calculation of costs.

**Domain:**

1	none
2	video camera
3	document camera

4	hand-held camera
5	scanner
6	video cassette recorder
7	projector
8	personal computer
9	video microscope
10	electronic stethoscope
11	otoscope
12	endoscope
13	ophthalmoscope/slitlamp
14	fundus camera
15	dermascope
98	other

**Guide for use:** Multiple devices may be recorded.

**Source:** Based on Telemedicine Glossary, 1998, *Telemedicine Today* 1998 Buyer's Guide & Directory.  
Reid, J, 1996, *A Telemedicine Primer: Understanding the Issues* Innovative Medical Communications, Billings MT, USA.

**Comment:** In telehealth, peripheral devices are used to augment communications and/or medical capability by capturing images, anatomic sounds or other physiological parameters. Non-medical peripheral devices are also useful.

**ITEM:**                      **Telecommunications Type**

**Definition:** Type of telecommunications technology utilised during a telehealth session.

**Context:** Telehealth

<b>Domain:</b>	1	telecommunications carrier services – ISDN, DDN/DDS, ATM
	2	dial on demand – POTS, ISDN
	3	permanent LAN connection – LAN to WAN, LAN to LAN, private networks
	8	other

---

9 unknown

**Guide for use:** ISDN = Integrated Service Digital Network  
DDN/DDS = Dedicated Digital Network/Digital Data Service  
ATM = Asynchronous Transfer Mode  
POTS = Plain Old Telephone Service  
LAN = Local Area Network  
WAN = Wide Area Network

**Source:** nil

**Comment:** In this context, telecommunications technologies are generic descriptors that include all infrastructure components that are used to connect telehealth equipment located at different sites. The technologies used may have implications for capital investment and recurrent costs.

**ITEM:**                    **Bandwidth**

**Definition:** Maximum bandwidth utilised by a site in a telehealth session.

**Context:** Telehealth. This data item provides information that may enable costs associated with telehealth to be calculated, and provide an indication of quality of carrier service for a session.

**Domain:**

1	up to, and including, 64 Kbps
2	128 Kbps
3	256 Kbps
4	384 Kbps
8	other
9	unknown

**Source:** nil

**Comment:** Bandwidth is a measure of the capacity of an electronic transmission medium (ie a communications channel) to transmit data per unit of time – the higher the bandwidth, the more data/information can be transmitted in a given time. Where two sites run at different speeds it is usual for the systems to negotiate the highest bandwidth possible between sites, usually this reflects the highest common standard or protocol that can operate between two units. Typically measured in kilobits or megabits per second (Kbps, Mbps).

**ITEM:**                    **Operational Problems**

**Definition:** Technical problems experienced by a site during a telehealth session.

**Context:** Telehealth. This data item can be a useful indicator of quality and safety.

**Domain:**

1	none
2	initial connection problem
3	transmission problem
4	image problem
5	sound problem
8	other

**Guide for use:** Multiple problems may be recorded.  
Initial connection problems include bandwidth problems.

**Source:** nil

---

**Table 9.3 - CLIENT**

A client is any person who receives or is the target of healthcare services. Clients are referred to as patients in many service contexts.

*Queensland Health Data Dictionary Version 2 Queensland Health 1998, Brisbane.*

**ITEM:**                      **Client Identifier**

**Definition:** Person identifier unique within establishment or agency.

**Source:** National Health Data Committee, 1999, *National Health Data Dictionary Version 8.0* Australian Institute of Health & Welfare, Canberra.

**ITEM:**                      **Date of Referral**

**Definition:** Date on which client was referred to further care.

**Context:** Telehealth. Together with 'Time of referral' and 'Urgency of telehealth service', this item can be used to determine whether telehealth is able to facilitate the provision of care in a timely manner.

**Layout:** DDMMCCYY

**ITEM:**                      **Time of Referral**

**Definition:** Time at which client was referred to further care.

**Context:** Telehealth. Together with 'Date of referral' and 'Urgency of telehealth service', this item can be used to determine whether telehealth is able to facilitate the provision of care in a timely manner.

**Layout:** HH:MM

**ITEM:**                      **Sex**

**Definition:** The sex of the person.

**Domain:**

1	male
2	female
3	indeterminate
4	not stated/inadequately described

**Source:** National Health Data Committee, 1999, *National Health Data Dictionary Version*

**ITEM:**                      **Date of Birth**

**Definition:**    The date of birth of the person. Report in format DDMMCCYY.

**Source:**        National Health Data Committee, 1999, *National Health Data Dictionary* Version 8.0 Australian Institute of Health & Welfare, Canberra.

**ITEM:**                      **Indigenous Status**

**Definition:**    An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives.

**Context:**        Given the gross inequalities in health status between Indigenous and non-Indigenous peoples in Australia, the size of the Aboriginal & Torres Strait Islander populations and their historical political context, there is a strong case for ensuring that information on Indigenous status is collected for planning and service delivery purposes and for monitoring Aboriginal and Torres Strait Islander health.

**Domain:**        1                    indigenous - Aboriginal but not Torres Strait Islander origin  
                      2                    indigenous - Torres Strait Islander but not Aboriginal origin  
                      3                    indigenous - Aboriginal and Torres Strait Islander origin  
                      4                    not indigenous - not Aboriginal or Torres Strait Islander origin  
                      9                    not stated (not for use in primary data collection)

**Source:**        National Health Data Committee, 1999, *National Health Data Dictionary* Version 8.0 Australian Institute of Health & Welfare, Canberra.

**ITEM:**                      **Area of Usual Residence**

**Definition:**    Geographical location of usual residence of the person.

**Guide for use:**   For approximate Statistical Local Area (SLA), need to record locality, postcode and state.

**Source:**        Based on National Health Data Committee, 1999, *National Health Data Dictionary* Version 8.0 Australian Institute of Health & Welfare, Canberra.



**ITEM:**                      **Presenting Problem Category**

**Definition:** The type of disease or disorder that was the principal reason for the telehealth session, as determined by the responsible healthcare worker at the referring site.

**Context:** This data item provides valuable information relating to the nature of the clinical conditions for which telehealth is used. Such information can be used to assist with planning and identifying areas where telehealth may be under-utilised or over-utilised.

<b>Domain:</b>	1	Diseases and Disorders of the Nervous System
	2	Diseases and Disorders of the Eye
	3	Diseases and Disorders of the Ear, Nose, Mouth and Throat
	4	Diseases and Disorders of the Respiratory System
	5	Diseases and Disorders of the Circulatory System
	6	Diseases and Disorders of the Digestive System
	7	Diseases and Disorders of the Hepatobiliary System and Pancreas
	8	Diseases and Disorders of the Musculoskeletal System and Connective Tissue
	9	Diseases and Disorders of the Skin, Subcutaneous Tissue and Breast
	10	Endocrine, Nutritional and Metabolic Diseases and Disorders
	11	Diseases and Disorders of the Kidney and Urinary Tract
	12	Diseases and Disorders of the Male Reproductive System
	13	Diseases and Disorders of the Female Reproductive System
	14	Pregnancy, Childbirth and the Puerperium
	15	Newborns and Other Neonates with Conditions Originating in the Perinatal Period
	16	Diseases and Disorders of the Blood and Blood Forming Organs and Immunological Disorders
	17	Neoplastic Disorders (Haematological & Solid Neoplasms)
	18	Infectious and Parasitic Diseases (Systemic or Unspecified Sites)
	19	Mental Diseases and Disorders
	20	Alcohol/Drug Use and Alcohol/Drug Induced Organic Mental Disorders

---

- 21 Injuries, Poisonings and Toxic Effects of Drugs
- 22 Burns
- 23 Factors Influencing Health Status and Other Contacts with Health Services

**Guide for use:** The domain is derived from a grouping of all the Diagnosis Related Groupings (DRGs) into 23 mutually exclusive principal diagnosis categories known as Major Diagnostic Categories (MDCs). Ultimately, they are derived from the assigned ICD-9/ICD-10 procedure and diagnosis codes.

**Source:** Australian Refined Diagnosis Related Groups (AR-DRG) Classification V4.1, Commonwealth Department of Health and Family Services, Canberra.

---

**Table 9.4 - HEALTHCARE WORKER**

Any person who delivers healthcare services to clients - this includes both direct services and support services. The definition of healthcare worker therefore includes medical staff, nursing staff, allied health professionals, indigenous health workers, and administrative staff.

**ITEM:**                      **Job Category**

**Definition:** Occupational category to which healthcare worker belongs.

<b>Domain:</b>	1	medical
	2	nursing
	3	allied health professional
	4	indigenous health worker
	5	dentistry
	8	other

**Comment:** Although similar in concept to the NHDD Item 'Classification of health labour force job', the above data item has been developed for two reasons:  
(1) the NHDD item does not appear to be complete – specifically, it does not include indigenous health worker, and it lists some allied health disciplines but not others, and  
(2) simplicity.

**Source:** nil

**ITEM:**                      **Employment Basis**

**Definition:** The employment arrangements under which the healthcare worker provides the telehealth service.

<b>Domain:</b>	1	public sector (provider is a permanent, contracted or sessional public sector employee)
	2	community sector (provider is an employee of a non-government or community-controlled organisation eg Home and Community Care (HACC), Silver Chain, Aboriginal Medical Service)
	3	private practitioner
	4	contracted by:
	4.1	worker's compensation
	4.2	insurance assessment
	4.3	Commonwealth Rehabilitation Service (CRS)

- 4.4 Department of Veterans Affairs (DVA)
- 4.5 employer
- 4.8 other

**Source:** nil

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**Table 9.5 - TELEHEALTH SERVICE**

Provision of client care. Includes both direct and indirect care.

<b>ITEM:</b>	<b><u>Clinical Care Activity</u></b>
<b>Definition:</b>	The principal activity carried out during a telehealth session, the purpose for which is clinical care.
<b>Context:</b>	Telehealth
<b>Domain:</b>	1 initial urgent evaluation for triage and transfer decisions 2 follow-up of treatment and medication checks 3 case discussion and review 4 diagnosis and general assessment 5 pre-admission assessment 6 discharge planning 7 one-off or continuing provision of specialty care, including therapy 8 patient education and preventative medicine 9 patient/family support 98 other
<b>Guide for use:</b>	Record major focus of session – includes both direct (client present) and indirect (client not present) forms of clinical care. Activities associated with patient/family support include, for example, linking the patient and other support networks in their home town. This has a number of benefits such as reducing the sense of isolation for the patient, allowing the inpatient treating team access to clinically relevant information and a sense of the patient's social context, and assisting with discharge planning.
<b>Source:</b>	Based on Grigsby, J, Schlenker, RE, Kaehny, MM, Shaughnessy, PW, & Sandberg, EJ, 1995, Analytic Framework for Evaluation of Telemedicine <i>Telemedicine Journal</i> Vol 1, No 1.
<b>Comment:</b>	This data item facilitates description of the nature of client care activities conducted via telehealth, including both direct and indirect client care activities.

<b>ITEM:</b>	<b><u>Urgency of Telehealth Service</u></b>
<b>Definition:</b>	The urgency of the required telehealth service, in the opinion of the referring practitioner.
<b>Context:</b>	Telehealth.

<b>Domain:</b>	1	emergency
	2	urgent
	3	routine

**Guide for use:** "Emergency" covers cases where the service could not be delayed more than 24 hours from the time of referral.

"Urgent" covers cases where the service was required within 7 days of referral. Other cases are coded as "routine".

**Source:** Definition, but not Domain, based on National Health Data Committee, 1999, *National Health Data Dictionary* Version 8.0 Australian Institute of Health & Welfare, Canberra.

**ITEM:**                    **Service Classification**

**Definition:** Type of service provided by the consulted practitioner in the telehealth session.

**Context:** Telehealth

<b>Domain:</b>	1	alcohol/drugs
	2	allergy
	3	audiology
	4	burns
	5	cardiology
	6	dentistry
	7	dermatology
	8	diabetes
	9	ear, nose and throat
	10	emergency medicine
	11	endocrinology
	12	gastroenterology
	13	general medicine
	14	genetics
	15	geriatric medicine

16	gynaecology
17	haematology
18	immunology
19	infectious diseases
20	intensive care
21	mental health
22	neonatology
23	nephrology
24	neurology
25	neurosurgery
26	nutrition/dietetics
27	obstetrics
28	occupational therapy
29	oncology
30	ophthalmology
31	optometry
32	orthopaedics
33	orthotics
34	paediatrics
35	palliative care
36	pathology
37	physiotherapy
38	plastic surgery
39	podiatry
40	prosthetics
41	psychiatry
42	psychology

43	radiology
44	rehabilitation
45	respiratory medicine
46	rheumatology
47	social work
48	speech pathology
49	spinal
50	surgery
51	urology
98	other

**Source:** Based on clinic classification from Cleary, M, Murray, J, Michael, R, Piper, K, 1998, Outpatient costing and classification: are we any closer to a national standard for ambulatory classification systems? *The Medical Journal of Australia* Vol 169 Supplement 19 Oct.

**ITEM:**                      **Participant Type**

**Definition:** Persons participating in or present at the telehealth session.

**Context:** Telehealth

<b>Domain:</b>	1	healthcare worker
	2	client
	3	family member/carers
	4	interpreter
	8	other

**Guide for use:** Each site records the people participating at the site for each category. The type is cross-classified by Participant count to determine how many people are present.

**Source:** nil

**ITEM:**                      **Participant Count**

**Definition:** Count of participants of each type involved in a telehealth session at the site.



**Context:** Telehealth

**Source:** nil

**Comment:** One of the advantages of telehealth is that it allows participation of greater numbers of people in a consultation than might normally be the case eg specialist at one end and referring practitioner, client and maybe family member(s) at the other. This has implications for funding.

**ITEM:**                      **Duration of Clinical Care Activity**

**Definition:** Length of time concerned with clinical care of an individual client during the current telehealth session.

**Context:** Telehealth. This data item allows assessment of actual time spent per client.

**Layout:** HH:MM

**Source:** nil

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## **Appendix B: Associations and Organisations to Contact for More Information**

CIHI	Canadian Institute for Health Information <a href="http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=pirc_e">http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=pirc_e</a>
CST	Canadian Society for Telehealth <a href="http://www.cst-sct.org/">http://www.cst-sct.org/</a>
ISO	International Standards Organisation <a href="http://www.iso.ch/iso/en/ISOOnline.frontpage">http://www.iso.ch/iso/en/ISOOnline.frontpage</a>
OECD	Organisation for Economic Co-Operation and Development <a href="http://www.oecd.org/">http://www.oecd.org/</a> <a href="http://www.oecd.org/health">http://www.oecd.org/health</a>

## **Appendix C:**

### **Description of Some Tools Identified and Further Resources.**

This appendix contains brief information regarding tools identified directly or indirectly through preparation of this Information Document. Where possible a web or literature reference is provided. This information is provided for information only. Their listing does not imply endorsement.

#### **C1. ADULT ASTHMA SURVEY (AOMS™)**

"The AOMS™, jointly developed by QualityMetric Incorporated (QM) and the Joint Council of Allergy, Asthma and Immunology (JCAAI) is a standardized, patient-based measure of asthma and its impact. It is a system for assessing and tracking functional health and well-being outcomes in asthma. The AOMS™ combines generic and asthma specific assessments with supplemental questions to assess the burden of asthma and the benefits of treatment. Components of the AOMS™ Adult Assessment include:

- Generic health status (SF-8™ Health Survey)
- Asthma-specific impact (ITG-ASF™ Asthma Short Form)
- Asthma severity, symptoms and flare-ups
- Activity limitations, including bed days and missed work/school days
- Adherence to prescribed treatments
- Utilization of healthcare resources (use of PCP, specialist, hospital and ER)"

<http://www.qualitymetric.com/innohome/inasthma.shtml>

#### **C2. CAREGIVER BURDEN INVENTORY**

Caregiver burden is associated with negative outcomes such as caregiver depression and increased likelihood of patient institutionalization. For information see Novack and Guest (1989a) and Novack and Guest (1989b), or the website:

<http://www.usherbrooke.ca/Cdrgg/reseau/instru/fa-i2.html>

#### **C3. COPING STYLES INVENTORY (CSI)**

The CSI assesses the extent to which a person uses certain coping thoughts and behaviors in response to a particular stress. The format of the CSI adapts 49 items from the Ways of Coping checklist (Falkman & Lazarus, 1980) sixty items were generated by the authors. Seventy two statements depicting various ways of dealing with terminal illnesses are rated by the respondents on a 5 item Likert format ranging from "not at all" to "very much". The CSI has eight components: problem solving, cognitive restructuring, express emotions, social support, problem avoidance, wishful thinking, and self-criticism and social withdrawal. The tool was used in a study of 44 spouses of patients admitted to Hospice. (Willert, M., Beckwith, B., Holm, J. and Beckwith, S. (1995). A preliminary study of the impact of terminal illness of spouses: social support and coping strategies. *The Hospice Journal*, 10(4), 35-48.). Reliability - the alpha coefficients for the primary factors of the CSI ranged from .71 to .94. Tested-retested reliability coefficients ranged from .67 to .83. Validity - no information provided. (See Tobin *et al.*, 1989).

#### **C4. ETHICAL ISSUE SCALE (EIS)**

Measures the frequency by which ethical issues occur in nursing. Thirty two (32) item scale that represents three conceptual categories of ethical issues: end-of-life treatments (n=13), patient care (n=14), human rights (n=5). Was developed from a 32-item scale used in a 1994 study of Maryland nurses. The items of the original scale were derived from the literature & focus groups interviews of practicing nurses. Reliability - end-of-life treatment issues scale = 0.86 (Cronbach's alpha coefficient); patient care issues scale = 0.84; human rights scale = 0.74. Can be used as independent scales. Validity - confirmatory principal components analysis of all items yielded a 3-component solution accounting for a total of 42.4% of initially extracted common variance. (See Fry and Duffy, 2001).

#### **C5. FAMILY ASSESSMENT DEVICE (FAD)**

The McMaster Family Assessment Device (FAD) is a short, self-report measure of family functioning that describes emotional relationships and functioning within the family. The FAD has been validated with a number of clinical populations including a low-functioning population receiving in-home family therapy (Clark, Barrett, & Kolvin, 2000; Pfendler, Sharrow, Slattery, & Bean, 1997). Kabacoff, Miller, Bishop, Epstein, and Keitner (1990) have assessed outcomes with a single administration of the FAD at termination from therapy.

Ridenour, Daley and Reich (1999) recommend using the General Functioning scale as a summary score of family functioning. Epstein, Baldwin, and Bishop (1983) recommend using family rather than individual means and looking at each scale. We compared three approaches to assessing outcomes using family means on FAD scales: assessing the statistical significance of change on outcome measures, identifying the magnitude of its change, and determining the percentage of families below clinical cut-offs at termination from therapy. (See Slattery *et al.*, 2001).

#### **C6. HEADACHE IMPACT SURVEY (HIT-6™)**

A short-form survey that provides three unique features: it is short, practical, and standardised; psychometrically sound with good validity and reliability; and conceptually clear, without overlap across subscales.

The psychometric performance of the HIT-6 is high, and it yields data that complements both generic outcomes measures and traditional clinical measures. The reliability of the HIT-6 indicates that it can be used without reservation for group-level analyses such as comparing treatments, evaluating outcomes at practice or plan level, as well as population monitoring.

Available as a dynamic computer-administered survey, DYNHA® HIT, and a static short-form questionnaire. HIT-6 is scored on the same scale as DYNHA® HIT in order to maintain comparability across instruments.

<http://www.qualitymetric.com/innohome/inhit6.shtml>

#### **C7. HEALTH STATUS QUESTIONNAIRE 2.0 (HSQ 2.0)**

An assessment tool from Pearson Assessments, HSQ 2.0 is an outcomes measurement tool that yields a profile of scores on eight health attributes, an index of health status change, and an indication of risk for the presence of a depressive disorder. The eight health attributes are: Health Perception, Physical Functioning, Role Limitations/Physical Health, Role

Limitations/Emotional Problems, Social Functioning, Mental Health, Bodily Pain, Energy/Fatigue. This instrument is designed to be easily administered via self-report, personal interview, or telephone interview.

Designed as a general outcomes measure to be used in all settings that provide primary or mental health care services, the HSQ 2.0 captures aspects of both physical and emotional health.

The HSQ 2.0 contains all items found on the OMS (Outcomes Management System) 36-Item Short Form Health Survey (SF-36®) and allows the user to score both instruments in a single administration.

[http://assessments.ncspearson.com/assessments/tests/hsq\\_2.htm](http://assessments.ncspearson.com/assessments/tests/hsq_2.htm)

#### **C8. JALOWIEC COPING SCALE**

This questionnaire concerns how one copes with stress and tension, and how one handles stressful situations, and assesses the frequency and helpfulness of specified coping strategies. It is a sixty item objective questionnaire that lists sixty specific coping behaviours. The researcher specifies the stressor under investigation by filling in the blank in an introductory paragraph. Participants indicate their responses to each item on two Likert scales, first identifying how often they have used the strategy, and second, indicating how helpful it has been to them. No information on reliability or validity. (See Jalowiec, 1989).

#### **C9. JOB SATISFACTION SCALE**

Measures job satisfaction. It is a 7-subscale instrument incorporating 52 items scored in a variety of ranges. Some questions are indicated on a 5 point Likert scale ranging from 1 = strongly disagree to 5 = strongly agree. Originally designed by Price and Mueller, 1981. Reliability - internal consistency: alpha = 0.86. Validity not provided. (See Packard and Motowidlo, 1987).

#### **C10. MCGILL PAIN QUESTIONNAIRE (MPQ)**

The MPQ is a 20 item (or 15 item for the 'short form' – MPQ-SF) questionnaire that provides quantitative measures of clinical pain in adults, based on reported signs and symptoms. It captures sensory, affective, and other qualitative components, and allows statistical analysis of data collected during clinical research and practice. It has been translated into multiple languages

#### **C11. McMASTER QUALITY OF LIFE SCALE (MQLS)**

The MQLS measures quality of life, which has been suggested as the best method for determining the effectiveness of various approaches to palliative care. The McMaster Quality of Life Scale taps four dimensions of quality of life: physical, emotional, social and spiritual. It contains 32 items rated on a 7 point numerical scale ranging from negative descriptors to positive descriptors. Reliability – inter-rater and intra-rater reliability was examined using repeated measures ANOVA; inter-rater reliability was lower than intra-rater reliability. Internal consistency: overall alpha was 0.80. Validity - construct validity was examined using a t-test for the two a priori hypotheses:  $p = 0.04$ : Concurrent validity was correlated to be statistically significant with the Spitzer index. (See Sterkenburg *et al.*, 1996).

## **C12. MINNESOTA LIVING WITH HEART FAILURE QUESTIONNAIRE (MLHFQ)**

The Minnesota Living With Heart Failure Questionnaire (MLHFQ) is a measure of a patient's perceptions of the effects of congestive heart failure on their life. This 21-item, self-administered questionnaire comprehensively covers physical, socioeconomic and psychologic impairments that patients often relate to their heart failure. A score based on how each person ranks each item on a common scale is used to quantify the extent of impairment and how it is affected by therapeutic intervention.

The MLHFQ has been translated and validated in the following foreign languages. The questionnaire, instructions for administration, License Agreement, key references, and the validity/reliability information can be obtained by sending a request to the [contact](#) information listed on this web site:

<http://www.mlhfq.org/>

## **C13. MOS SHORT FORM - 20-ITEM (MOS-20) SCALE**

The MOS-20 measures general health concepts for use in evaluating health care. Research has shown that the McMaster Health Index, Sickness Impact Profile, Functional Status Questionnaire, Duck-UNC Health Profile, RAND Health Experience Measures, Nottingham Health Profile and Index of Well Being were instruments too long to be practical in most clinical settings. Thus, a compromise between lengthy instruments and single-item measures was sought. Twenty items were selected to represent six health concepts: (1) physical functioning, (2) role functioning, (3) social functioning, (4) mental health, (5) health Perceptions, and (6) pain. The resulting MOS-Short form is a 20-item scale. Items are scored on a 5 point Likert Scale.

Reliability - coefficients ranged from 0.81 to 0.88 for the multi-item scale. Internal consistency reliabilities were lower than the full length versions: health perception subscale = 0.87 (0.88 for 9 item version); mental health measure subscale = 0.88 (0.96 for the 38 item version); physical function subscale = 0.86 (0.90 for the 10 item version); role subscale = 0.81 (0.92 for the 3 item version). Validity - all correlations were statistically significant:  $p < 0.01$  and most were substantial in magnitude. (See Stewart *et al.*, 1988).

## **C14. PROFILE OF MOOD STATES INVENTORY (POMS)**

Measures patient distress. Adjectives are used to describe feelings and moods. Individual scores for tension, anger and depression are used by Olson in the study. Consists of 65 questions scored on a 5-point scale. Reliability - high reliability including good internal consistency. Validity - content validity was confirmed by factor analysis of eight mood factors. (See Olson, 1995).

## **C15. QUALITY OF WELL BEING (QWB) SCALE**

The QWB provides an estimate of the value of health status necessary for cost-utility analyses. Also, to quantify health-related quality of life with a single number that represents community-based preferences for combinations of symptom/problem complexes, mobility, physical activity, and social activity. The QWB Scale identifies a health related symptom that is most undesirable and grades it by the degree to which it affects everyday activities. By using QWB assessment, a single number is developed that represents the current impact of disease.

QWB scores are derived from preference weights for combinations of symptom/problem complexes and classification of functioning in terms of mobility, physical activity, and social activity obtained from a San Diego general population sample of 867 individuals. These preference weights were obtained in the mid 1970s but a 1991 study of Oregon citizens yielded very similar results. (See Kaplan, R.M. & Anderson, J. P., 1988).

#### **C16. SATISFACTION WITH DECISION SCALE (SWD)**

The SWD measures patient satisfaction with health care decisions. It is a six-item scale and each item is scored on a 5 point scale ("very certain would not take " to "very certain would take"). It can be used in health care settings to evaluate decision-assisting technologies or patient -provider interactions aimed at involving patients in decision making.

Patient satisfaction measures have previously addressed satisfaction with medical care, satisfaction with providers, and satisfaction with outcomes, but not satisfaction with the health care decision itself. The SWD was developed in the context of post-menopausal hormone-replacement therapy decisions to help understand specific dynamics of the decision itself.

Reliability - Cronbach's alpha is 0.86. Validity - discriminate validity, tested by performing principal-components analysis of items pooled from the SWD scale and two conceptually related measures, was good. (See Holmes-Rovner *et al.*, 1996).

#### **C17. SF-8™ - A NEW SHORT-FORM FOR MONITORING HEALTH OUTCOMES**

The SF-8™ Health Survey represents a major advance in the application of SF technology for purposes of achieving both brevity and comprehensiveness in population health surveys. It has only eight questionnaire items. By relying on a single item to measure each of the eight domains of health in the SF-36® Health Survey, the SF-8™ represents the ultimate phase in the evolution of SF assessments - single-item scales.

SF-8™ is also the first SF survey to be constructed on the basis of empirical studies linking each questionnaire item to a comprehensive "pool" of widely used questionnaire items, including but not limited to the SF-36®, proven to measure the same health concept. Because the item "pool" for each of the eight health concepts was calibrated on the same metric as the corresponding SF-36® Health Survey scale, each SF-8™ single-item scale and the SF-8™ summary measures can be scored on the same norm-based metrics as the SF-36® scales and summary measures. Thus, the SF-8™ is an 8-item version of the SF-36® that yields a comparable 8-dimension health profile and comparable estimates of summary scores for the physical and mental components of health.

The SF-8™ provides the long awaited "missing link" - a practical tool for directly linking the norms from large population surveys with the results from more focused clinical trials, outcomes research studies, and monitoring efforts in everyday clinical practice. The SF-8™ was constructed to replace the SF-36® and SF-12® in population health surveys in the U.S. and internationally. Accordingly, it has been translated and linguistically validated for use in more than 30 countries and languages using IQOLA Project methods. It has been adopted by federal agencies (e.g., the DOD), leading polling organizations (e.g., the Roper-Starch Worldwide Health Report), and industry sponsors of clinical trials and effectiveness research (e.g., Glaxo Smith Kline, Johnson & Johnson, and Searle).

<http://www.qualitymetric.com/innohome/insf8.shtml>

#### **C18. SF-12<sup>®</sup> HEALTH SURVEY**

A 12-item (two minute) questionnaire that was developed from the SF-36<sup>®</sup> Health Survey for use in monitoring outcomes for general and specific populations. This survey form has been shown to yield summary physical & mental health outcome scores that are interchangeable with those from the SF-36<sup>®</sup> in both general & specific populations. This short-form - the SF-12<sup>®</sup> - which was published in early 1995 is already one of the most widely used surveys. For background information on the development of these surveys visit [www.sf-36.com](http://www.sf-36.com).

This 12-question survey generates an abbreviated health profile consisting of two summary measures describing health-related quality of life. The SF-12v2<sup>™</sup> has been shown to yield summary physical and mental health outcome scores that are interchangeable with those from the SF-36<sup>®</sup> in both general and specific populations. It has been used extensively as a screening tool. Because of its brevity, it is frequently imbedded into longer, condition-specific surveys.

<http://www.qualitymetric.com/innohome/insf12.shtml>

#### **C19. SF-36<sup>®</sup> HEALTH SURVEY**

The SF-36<sup>®</sup> Health Survey is the most widely used patient-based health status survey in the world. The survey has been translated into more than 40 languages and administered to millions of people worldwide. This 36 question, comprehensive short-form generates a health profile consisting of 8-scales and two summary measures describing health-related quality of life. It should take 5 minutes to complete.

As documented in more than 1600 publications, the original SF-36<sup>®</sup> has proven useful in (1) monitoring general and specific populations, (2) comparing the burden of different diseases, (3) differentiating the health benefits produced by different treatments, and (4) screening individual patients. SF-36<sup>®</sup> is the most widely used health status instrument in the world.

The new Version 2.0 of the SF-36<sup>®</sup> Health Survey (SF-36v2<sup>™</sup>) was developed by QualityMetric staff, to improve upon the original SF-36<sup>®</sup> Health Survey. SF-36v2<sup>™</sup> Health Survey incorporates changes that significantly improve the wording and format of the form, and the precision of the role-functioning scales, with no change in respondent burden. In addition, the inclusion of norm-based scoring, and the version 2 technologies of missing data estimation and data quality testing allow for superior results.

<http://www.qualitymetric.com/innohome/insf36.shtml>

#### **C20. SICKNESS IMPACT PROFILE (SIP)**

Measures outcomes of contact with the health care delivery system, as well as health status based on functioning. Sickness Impact Profile contains 136 items grouped into 12 dimensions of daily activity; sleep and rest, emotional behavior, body care & movement, home management, mobility, social interaction, ambulation, alertness behavior communication, work, recreation & pastimes, and eating. Respondents check those items that apply to them at the time of the interview.

Although the need for a method of measuring the quality of life of patients undergoing therapy for cancer has been widely recognized, no adequately evaluated or feasible method has been established. Thus the SIP was developed as an outcome measure of overall health as a consequence of the use of the health-care delivery system.



Reliability - the SIP'S test-retest reliability was reported by Pollard and associates (1976). After a 24-hour interval, the correlation between the test-retest situation was 0.88 ( $p < 0.01$ ). Several other combinations of test-retest procedures were undertaken (e.g., long-form versus short-form; interviews administered versus self-administered); all combinations of these different conditions had correlations that were significant at  $p < .01$ . In addition, test-retest reliability correlation for each of the 12 dimensions are of the same magnitude of significance.

Validity - the item pool was selected from responses by "over 1000" persons who mentioned 1,250 specific dysfunctions of behavioral changes that were related to health (Gilson et al., 1975). By various grouping and testing procedures, this list was reduced to the current number of items. Various experiments related to the validity of the instrument were reported by Bergner, Bobbitt, Pollard, Martin and Gilson (1976). The successful ( $p < 0.001$ ) tests of validity indicated that the SIP percentage score correlates with self-assessment of sickness ( $r = 0.54$ ), self-assessment of dysfunction ( $r = 0.52$ ); the Activities of Daily Living Index (Spearman rank-order correlation = 0.46), a clinical assessment of dysfunction ( $r = 0.49$ ) and the activity limitation question on the National Health Interview Survey ( $r = 0.61$ ). (See Selby et al., 1984).

## Appendix D:

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