## Report of the NTOIP Workshop - 2003

November 2003





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# National Telehealth Outcome Indicators Project [NTOIP]

'A Canadian Consensus Approach to Identification and Definition of Outcome Indicators for Evaluation of Telehealth'

#### Report prepared by:

Bonnie Rush, MSc, Research Associate Dr. Maryann Yeo, Research Associate Dr. Richard E. Scott, Associate Professor

#### **Co-Investigators:**

Dr. Richard E. Scott Dr. Frank McCarthy Dr. Penny Jennett

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Contact: Dr. Richard E. Scott	Global e-Health Research and Training Program Health Telematics Unit University of Calgary G204 Health Sciences Centre 3330 Hospital Drive NW Calgary, Canada T2N 4N1
	403-220-6845
	email: htufloat@ucalgary.ca
Recipient Use	

#### **List of Abbreviations**

AHW Alberta Health & Wellness

CHA Canadian Health Act

CHIPP Canada Health Infostructure Partnerships Program

CIHI Canadian Institute for Health Information

COI Candidate Outcome Indicator

EU European Union

FMM First Ministers Meeting
HTU Health Telematics Unit
IOM Institute of Medicine

ISO International Standards Organization

MID Minimum Influential Dataset

NIFTE National Initiative For Telehealth

NTOIP National Telehealth Outcome Indicator Project

OECD Organization for Economic Co-operation and Development

TOD Telehealth Outcome Development

WOW Web of Wisdom

#### **Executive Summary**

The Health Telematics Unit at the University of Calgary hosted the first **National Telehealth Outcome Indicator Project Workshop** (NTOIP workshop) in June 2003. Participants included members of the professional, academic, government, and operational sectors interested in outcome indicators, some of whom had attended a brief informal discussion group around outcomes at the CST 2002 meeting in Toronto. During the NTOIP Workshop, they actively engaged in discussions on identifying and defining outcome indictors that could be used by the broader telehealth community when comparing or performing evaluations of telehealth applications.

This report is a compilation of the NTOIP Workshop presentations, breakout discussions, and reconvened group discussions, as well as key accomplishments and next steps. A draft of this report was distributed to all NTOIP participants to encourage feedback and ensure accuracy of the content. Dissemination of the report will be achieved through e-mail distribution and placement on the NTOIP Webpage at: <a href="https://www.ucalgary.ca/ntoip">www.ucalgary.ca/ntoip</a>, with links from other sites.

As a prelude to the workshop, the Telehealth Outcomes Development (TOD) framework and key outcomes definitions proffered in the NTOIP Information Document were reviewed and discussed. Although it was recommended that the TOD framework be transformed, it was agreed that it offered a simple, logical, and sequential process that could be followed when developing outcome indicators, and that it could be employed by a wide variety of audiences, including non-researchers and non-evaluators. In addition it was agreed that the generic definitions of e-health outcome, indicator, measure, and tool helped clarify the current confusion in the field and in the literature.

Four themes underscored the NTOIP Workshop: Quality and Access Indicators; Acceptability and Cost Indicators; Economic Evaluation; and Dissemination of Indicators.

#### Theme 1: Quality and Access Indicators

Two presentations approached this theme from a national perspective. The first explored the purpose of the CHIPP Evaluation Framework and how the CHIPP Framework addressed quality of care and accessibility. The second presentation reviewed the literature on quality and access, as documented in a recent State of the Science Review and the NTOIP Information Document. Ensuing debate resulted in a total of 12 Candidate Outcome Indicators (COI's) being identified for quality, and 6 for access, each of which will move forward to the consensus phase of NTOIP. There was agreement that the telehealth sector should not 'reinvent the wheel' and, where possible and appropriate, should align with existing outcome models and adopt indicators actively being developed in the larger health arena.

#### Theme 2: Acceptability and Cost Indicators

Two presentations explored this theme from both a practical and theoretical perspective. The first presentation under this theme detailed how research in telehealth must change to incorporate new models, new philosophies, and transform approaches to better evaluate e-health applications in regards to acceptability. The second presentation provided an introduction to a developing web-based costing tool that models expenses for equipment, network rental, staffing, network usage, and bridging / gateway usage, and other costs. Based on discussion, a total of 15 COI's were identified for acceptability, and 11 for cost, each of which will move forward to the consensus phase of NTOIP. Three outcome measures were also identified for cost. It was agreed that the societal perspective should be adopted when performing costing exercises, and that it was necessary to tailor cost studies to the needs of decision-makers in order for them to have

impact. It was also noted that acceptability and costing estimates will change over time to reflect what is important at any given moment.

#### Theme 3: Economic Evaluation

This presentation focused on the economic evaluation of telehealth applications, noting the pros and cons of various models. Five main economic evaluation techniques were described: cost description analysis, cost minimization analysis, cost benefit analysis, cost-effectiveness analysis, and cost utility analysis. A summary of the telehealth literature regarding economic evaluation was also detailed. No single model could be identified as best for evaluation of telehealth applications. However, it was noted that compromise must be achieved between academic quality and immediate access to interpreted information. Thus information that is less than 'academic quality' can still be useful if it is interpreted appropriately, distributed rapidly, and disseminated to the right audience.

#### Theme 4: Dissemination of Indicators

The last two presentations of the Workshop focused on the theme of dissemination of indicators. The first presentation introduced the concept of change as a way of moving from the status quo (frozen state), unfreezing, and moving to a new status quo. Readiness was defined as the willingness to embark upon this process. This state is required if we are to collectively move forward with standardized indicators and measures. Desirable characteristics and criteria for indicators and measures were shared. The final presentation explored why it is important to adopt consistent and defined outcome indicators, as a tool with which to gain support from the broader telehealth community as the NTOIP process moves forward.

#### **Overall Conclusions and Recommendations**

Participants offered conclusions and provided recommendations for resolution of issues they identified during the course of the Workshop. Examples are shown below:

#### Conclusions:

- ➤ The Telehealth Outcomes Development (TOD) Model is a good starting point.
- > Transformation of the conceptual TOD model to a practical tool is desirable.
- Consensus on what indicators should be used on a consistent basis has yet to be resolved.
- A "Minimum Influential Dataset" (MID) that illustrates by real-life examples how telehealth has affected individual and societal health values (need, equity, cost, quality, access, impact, and outcome) would be valuable. MID activities were initiated, and require further work.

#### Recommendations:

- A consultation process is needed to gain feedback from the broader telehealth community for consensus around Candidate Outcome Indicators.
- It is very important to disseminate the <u>process</u>, as well as the results of this NTOIP Workshop to a broader audience.
- It will be important to encourage future collaboration and cooperation with organizations (e.g. Canadian Society of Telehealth (CST); Canadian Institute for Health Information (CIHI); and others) to further the outcomes work.

A notable underlying theme that emerged was the overall need for *consistent terminology* within the telehealth and e-health fields

#### Summary

The NTOIP Workshop, conducted at the University of Calgary in June 2003, provided a forum for interested participants from government, academia, professional, and operational sectors to actively engage in discussion around development and dissemination of telehealth outcome indicators, as well as desirable economic evaluation models for telehealth evaluation. There was great discussion during breakout sessions that revealed diverse opinion on many topics, and finding consensus was not straightforward. This report focuses primarily on points of general agreement.

NTOIP represents an important first step in analyzing the complex issues surrounding the advancement and uptake of telehealth within the Canadian healthcare system. The Workshop and the ensuing dialog will help develop the groundwork for additional movement in the areas of evaluation, outcome indicators, and dissemination.

#### **Acknowledgements**

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The investigators gratefully acknowledge the support provided by the NTOIP Workshop participants, who willingly and openly debated many central and peripheral issues related to telehealth outcomes.

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#### Overview

The Health Telematics Unit (HTU) at the University of Calgary hosted the first **National Telehealth Outcome Indicator Project Workshop** (the 'NTOIP workshop') in late June 2003. Participants included members of the professional, academic, government, and operational telehealth sectors interested in outcome indicators (see Appendices 1 and 2 for a full listing of NTOIP participants and speaker biographies). Participants were actively engaged in discussions around identifying and defining outcome indictors that could be used by the broader telehealth community when comparing or performing evaluations of telehealth applications. Four themes underscored the NTOIP Workshop: Quality and Access Indicators; Acceptability and Cost Indicators: Economic Evaluation; and Dissemination of Indicators.

The objectives of the NTOIP Workshop were to:

- Bring together leaders in telehealth research and evaluation to discuss outcome indicators and related economic evaluation and dissemination issues;
- Review a summary report of the telehealth outcomes literature NTOIP Information Document;
- ➤ Identify candidate telehealth outcome indicators in four areas Quality, Access, Acceptability, and Cost;
- Identify which economic evaluation model is best suited to evaluate telehealth applications;
- Confirm and initiate the telehealth outcome indicator definition process;
- Identify how outcomes indicators are to be presented and disseminated to ensure acceptance and adoption by the broader telehealth community:
- Produce a Working Document that will be disseminated to NTOIP participants and the broader telehealth community to encourage additional dialogue on the issues of outcome indicators, economic evaluation, and dissemination.

All but one of these was achieved. Time constraints prevented a thorough discussion around the fifth objective ('confirm and initiate the telehealth outcome indicator definition process'). As a consequence, the investigative team took on this task subsequently.

The full Workshop Syllabus can be found in Appendix 3. Formal presentations or panels were used to provide information and stimulate discussion, and breakout sessions were then used to encourage greater individual input. Appendix 4 lists the questions and guidelines that were used to focus breakout sessions. Reconvening for collective reports of the breakout sessions ensured participants as a whole remained informed. An experienced and knowledgeable telehealth practitioner led each breakout session. Rapporteurs captured the thoughts and opinions offered by participants, which were collated and synthesised to form the basis of this report.

The report is presented as a series of sequential sections. For most Sections a similar format has been adopted:

- a summary of 'key points' for the section;
- a brief summary of the formal presentations for that section;
- summary notes taken from the breakout and reconvened sessions; and
- recommendations or conclusions that could be drawn from the session.

Great effort was made to capture the *major themes and concepts* presented by participants during discussions and to use these in preparing recommendations.

Some points of clarification have been added after the workshop to provide additional perspective. They were not a part of the workshop and have been clearly differentiated by [appearing as italicized text within square parentheses].

#### 1. Preamble

#### **Key Points:**

- The Telehealth Outcomes Development (TOD) framework provides a simple, logical, and sequential process to follow when developing outcome indicators.
- TOD could be employed by a wide variety of audiences, including nonresearchers and non-evaluators.
- A modified TOD framework is desirable, and expected to evolve over time.
- Where possible existing outcome indicators, measures, or tools should be adopted.
- The generic definitions of e-health outcome, indicator, measure, and tool help clarify the current confusion in the field and literature.
- Terms used to describe e-health outcome measures must be clear; e.g. not simply 'time' or 'distance' but, for example, 'time saved by patient' / 'distance traveled by nurse'.

This section provides a brief overview of the Telehealth Outcomes Development (TOD) framework and outcome indicator definitions as a contextual background for the reader. These were two key aspects presented in the NTOIP Information Document<sup>1</sup>, which was provided to workshop participants prior to the meeting for their review. During the early stage of the Workshop, participants were given the opportunity to discuss and critique these aspects, and the points they raised during discussion are integrated into the background provided below.

#### 1.2 The TOD Framework

The TOD framework, as taken from the NTOIP Information Document (pp 62 -68)<sup>1</sup>, is intended to provide a conceptual framework and structured process with which to approach outcomes development. The five domains of the TOD framework are: category, theme, indicator, measure, and tool. The figures below illustrate the five domains of TOD (Figure 1) and the overall concept of the TOD framework (Figure 2) when populated with hypothetical content.

The TOD framework supports a logical and comprehensive outcome indicator development process where 'outcomes' are to be assessed. As such, it was presented as a conceptual framework, not a defined tool. Thus categories are presented first, followed by themes within which the outcomes assessment will be framed. Only thereafter are clear outcome indicators described, followed by description of the specific measures and tools that will be used.

#### 1.2.1 Discussion around the TOD Framework

NTOIP workshop participants were asked to discuss the usefulness of the TOD Framework in providing a structured process for outcomes development.

There was a general agreement amongst the NTOIP participants that the TOD framework provided an excellent starting point. There was also agreement that TOD was a useful and logical model that could be employed by a wide variety of audiences, including non-researchers and non-evaluators. As one NTOIP participant noted:

The TOD framework is not perfect, but it is a beginning.

(Workshop Participant)

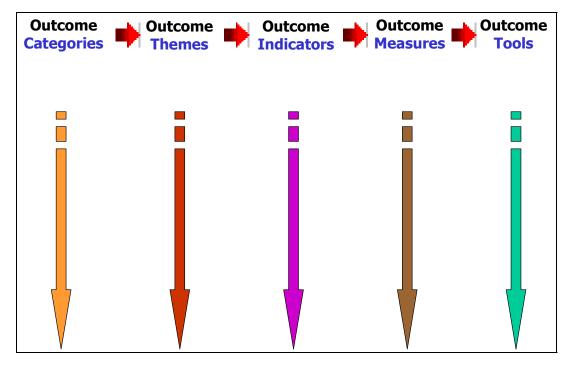


Figure 1: The Five Domains of the TOD Framework

Outcome Categorie		Outcome Themes	-	Outcome Indicators		Outcome Measures	Outcome Tools
Category 1	•	Theme 1	•	Indicator 1.1 Indicator 1.2 Indicator 1.3 Indicator 1.4	•	Measure 1.1 Measure 1.2.1 Measure 1.2.2 Measure 1.3 Measure 1.4.1 Measure 1.4.2	Tool 1.2 Tool 1.2 Tool 1.2 Tool 1.3 Tool 1.4 Tool 1.4
	•	Theme 2	•	Indicator 2.1 Indicator 2.2 Indicator 2.3	•	Measure 1.4.3 Measure 2.1 Measure 2.2.1 Measure 2.2.2 Measure 2.3	Tool 1.4  Tool 2  Tool 2.2  Tool 2.2  Tool 2.2  Tool 2.3
Category 2	<b>⇒</b>	Theme 3 etc.	•	Indicator 3.1 etc.	•	Measure 3.1 etc.	Tool 3.1 etc.

Figure 2: Illustration of the Overall Concept of the TOD Framework

There was division amongst participants about whether the TOD framework should be expanded to include additional themes that are integral to telehealth applications, e.g. use, perspective, etraining, health promotion and clinical divisions. One segment felt this would significantly enhance the breadth and utility of the framework. The other segment suggested that by adding more themes and definitions to the framework it would become too complex and / or specific to be useful as a conceptual framework, as had been intended.

There was also concern expressed that the TOD framework was to be "written in stone" and was to be "officially" adopted by the group during the workshop. Participants were reassured that the TOD framework was simply being offered to stimulate discussion, and there was no expectation that participants needed to give their 'sanction' to TOD as presented. Ongoing discussion revealed a desire to revise the TOD framework, although the precise objectives of the revisions were unclear. The final result remains unknown and the TOD framework will be revised and developed over time. The first attempts at modifying the TOD framework are detailed later in this report (Section 7).

One breakout group raised the issue of evaluating 'process' using the TOD framework, i.e. that the outcomes of the process need to be measured too. It was clarified that since measuring aspects of process is integral to evaluation, use of the TOD framework does not remove or impede this aspect, and in fact assists it. It was countered that regardless of what evaluation model or approach is used, the TOD framework is general enough to guide the outcomes aspect of any evaluation process (i.e. the framework is not evaluation model specific).

Another breakout group suggested the need to include the concept of *outputs* within the framework. Some suggested that the degree of information gained by assessing outcome measures may vary from the micro (which is seen through impacts) to the macro level (as seen through the <u>outputs</u> of any telehealth application). However, this was not the intent of the original TOD framework, which viewed impact as the effect and output as the result, which would be assessed by an outcome indicator. [Care is necessary in using the term 'output'. The literature indicates that this is often used to refer to some tangible report / document etc. emanating from a study or some other activity, rather than being used to refer to some specific result of an intervention.]

There was general agreement amongst the participants that the TOD framework provided a logical and sequential process for outcome development that could prove to be useful.

#### 1.3 Outcome Indicator Definitions

A second important component of the NTOIP Workshop was to obtain consensus on the definitions provided for various dimensions of outcomes. Certain 'domains' had been created specifically for use in the TOD framework (e-health outcome *category*, e-health outcome *theme*), but the definitions of e-health outcome, e-health outcome indicator, e-health outcome measure, and e-health outcome tool were intended to be generic, and for use by the broader e-health community. It should be noted that these definitions were originally formulated as being 'telehealth' specific, but were quickly seen to be equally applicable when considering 'e-health' as an overarching term that encompasses telehealth. They were deliberately presented as 'e-health' related terms in the NTOIP Information Document to emphasise this point. To provide context, the following definitions have been abstracted from the NTOIP Information Document (pp 63-64)<sup>1</sup>.

#### 1.3.1 TOD Framework Related Definitions

**'e-Health Outcome <u>Category'</u>** 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, and Non-Health Determinants.

**'e-Health Outcome <u>Theme</u>'** has relied upon the IOM model<sup>2</sup> to describe essential areas of focus for evaluation: Quality, Access, Acceptability, and Cost.

#### 1.3.2 Generic 'Outcome' Definitions

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

**'e-Health Outcome** <u>Indicator</u>'. 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, and Availability.

**'e-Health Outcome Measure'.** 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, and Rurality.

'e-Health Outcome <u>Tool'</u>. The specific instrument used to collect quantitative or qualitative data for any single outcome measure. Examples 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).

#### 1.3.3 Discussion around Outcomes Definitions

Participants noted the confusion that exists around differentiating between outcomes, outcome measures, and outcome tools. For example, the terms "indicator", "measure", and "tool" are often used interchangeably in the telehealth / e-health literature, and in the field. It was also identified that the differentiation was not always clear in the examples provided with the TOD framework in the Information Document, which inadvertently added to (rather than clarified) the confusion.

There was general consensus amongst NTOIP workshop participants that the definitions supplied were adequate, and that their adoption should be encouraged. One group noted that a single tool might often measure more than one thing. Another breakout group suggested that, given the subjective nature of any outcome indicator definition, it might be beneficial to avoid using one-word terms as a catch-all description, e.g. using as an outcome measure 'time'. A clearer method of describing a measure would be through the use of a qualifying phrase instead of only one word. An example would be to use the qualifying measure of "save time and travel" to clearly describe the cost saving attributed to a particular telehealth intervention. [The intent of this proposal is good, but in reviewing the literature several concerns arise; a) this presents an immediate bias, assuming as it does that an e-health intervention will 'save' time and travel, b) it provides a 'double-barrelled' measure - time and travel, which may present difficulty (in general it is best to identify one element only, i.e. time or travel), and c) use of such terms as 'change in ..' cause difficulty, because there is not always a non-e-health comparator against which to measure].

Participants were certainly in agreement that, where possible, existing indicators, measures, or tools should be adopted, i.e. it is unnecessary to reinvent the wheel. This includes examining alignment with existing regional, national, and international efforts at identifying outcomes in the health (not telehealth or e-health) sector.

#### 1.4 Recommendations

- The conceptual TOD framework and generic outcome definitions should be disseminated for broader critique.
- Transformation of the original conceptual TOD framework into a practical tool should be pursued.

#### 2. Quality and Access

#### **Key Points:**

- Don't reinvent the wheel. Use and adapt models, definitions, indicators etc instead of creating from scratch.
- The final report from CHIPP, which will bring together indicators from 29 projects, will be a rich source in the future regarding outcome indicators.
- 'Candidate outcome indicators' need to move towards a consensus process.
- Consistent terminology is needed for Quality and Access.

#### 2.1 Introduction

The NTOIP Workshop was divided into themes. Within each theme a specific question was posed for discussion by participants. Theme 1 focused on quality and access, and the question for Theme 1 was:

Which specific outcome indicators / measures are most suitable for broad evaluation of telehealth applications for Quality and Access?

#### 2.2 Presentations

Two presentations approached this theme from a national perspective. The first explored the purpose of the CHIPP Evaluation Framework and how the CHIPP Framework addressed quality of care and accessibility. The second presentation reviewed the literature on quality and access, as documented in a recent State of the Science Review, and in the NTOIP Information Document.

## 2.2.1 National Telehealth Outcomes Indicator Project: Quality of Care and Accessibility Indicators – CHIPP Preliminary Results. Sandra Chatterton, Health Canada.

The CHIPP Evaluation Framework had several purposes: a) to contribute to the evaluation of CHIPP outcomes and impact, b) to ensure projects were indeed evaluated (both formative and summative evaluations), c) to contribute to the knowledge base, and d) to provide a responsive policy and program development process. The CHIPP<sup>3</sup> model expanded upon the IOM model<sup>2</sup> by including elements such as: integration, health and related impacts, technology performance, privacy, rationale and lessons learned.

Current activities that address quality of care include: (1) the First Ministers Agreement (FMM)<sup>4</sup> which is to develop a framework of health and health system performance indicators (of which there are 11 priority areas – where #5 deals with the Electronic Health Record), (2) the FMM/CIHI initiative to address the dimensions of quality, as taken from the CIHI Health Indicator Conceptual Framework (includes elements such as safety, effectiveness, efficiency and continuity), (3) the OECD<sup>5</sup> initiative which is developing indicators for the technical quality of medical care, and (4) NTOIP – where 33 of110 articles examined quality.

The Definition of Quality as stated by Bashshur<sup>6</sup> needs to be adapted to reflect that 'technical quality' refers to the process of care (which is both technical and clinical). Standards will have to be developed to ensure that services are delivered the same way both clinically and technically.

Current activities that address accessibility of care include: IOM, NTOIP, Canada Health Act, the International Standards Organization (ISO), and the FMM. The CHIPP Model Framework adapts the IOM Model when assessing accessibility to include the following factors: distance and transportation, recruitment, retention, and reduction of isolation for health professional, socioeconomic factors, and delivery system coordination. The enhancements are considered important advances in outcomes analysis.

## 2.2.2 Socio-economic Indicators of Quality and Access. Penny Jennett, University of Calgary.

This presentation began with an outline of the social economic benefits that have been attributed to telehealth (e-health) <sup>7</sup>. It then moved to focus on two themes: quality and access, beginning with how historically these have been addressed. To facilitate participant discussion, the presentation concluded with primary definitions, secondary definitions, working definitions, measures, and chart examples specific to the two themes <sup>1</sup>.

Persons interested in these two themes were directed to the historical work by the Canadian Institute for Health Information, the International Standards Organization, the European Union, and Austraila<sup>1</sup>, as well as to a recent study<sup>7</sup>. In the latter, of the just under 110 articles reviewed, nine areas of social economic benefit were outlined: access, costs, utilization, health outcomes, quality of care, quality of life, acceptability/satisfaction, social isolation, support and education. More specifically, related to quality, 26 articles examined some primary or secondary aspects of quality (e.g. quality of life, quality of care, safety, efficacy, effectiveness, continuity of care, comprehensive care, self-care), and 24 discussed primary or secondary aspects of access (e.g. ease in obtaining health services, timeliness, convenience)<sup>7</sup>.

The Working Definitions, as defined by the IOM Model<sup>1, 2</sup>, for Quality and Access are:

**Quality** (of care) – "the degree to which the health care services for individuals and populations increase 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."

Quality was ascertained via questionnaire, in-person (or telephone) interviews, needs assessment, and content analysis. To assess quality a number of tools have been used: the Coping Response Indices, the SF-26, the Caregiver Burden Inventory, and the Health Status Questionairre<sup>1</sup>. Databases, registries, logs and National groups (e.g. Statistics Canada) were viewed as tools for data related to access.

Flow charts for the two themes, Quality and Access, were provided. These presented sample indicators, measures, and tools for the two areas<sup>1</sup>.

#### 2.3 Group Discussion

Which specific outcome indicators / measures are most suitable for broad evaluation of telehealth applications for Quality and Access?

#### 2.3.1 Outcome Indicators of 'Quality'

There was considerable discussion around how standards directly affect quality and access. The application of any measure for quality and access (which tend to vary from jurisdiction to jurisdiction) needs to be responsive to issues such as local standards of care, as well as national and international standards, where appropriate. Currently, there has been much activity around

the development of standards and indicators in the healthcare arena. One Canadian telehealth related example is the National Initiative for Telehealth (NIFTE) Guidelines<sup>8</sup>. It was also noted that access may be considered a part of quality, and therefore differentiation between 'quality' and 'access' might be artificial and unnecessary.

As a group, definitions for quality and access were agreed upon (see below). However, there was no clear consensus on what indicators should apply to each theme. Some members were of the opinion that deciding on five indicators for the themes of quality, access, acceptability and cost would be premature – that it is better decided via a Delphi Process. [As noted in the Information Document, the intent is to seek a broader consultation via a web-based consensus process].

The definition for quality was felt by the group to be best described by Hailey and Jacobs<sup>9</sup>. Quality can therefore be defined as: *Those relevant characteristics, other than time, which influence the experience obtained from the use of telehealth* 

In regards to specific definitions and indicators around quality (and the other outcome themes), it became apparent from discussion that group members encouraged the concept of adapting existing indicators instead of developing new ones.

Use what is already out there, such as the Road Map Initiative definitions, and adapt the definitions to better suit your needs.

(Workshop Participant)

As this is a national initiative, we should align our definitions and measures for quality with that of other national movements such as the Road Map Initiatives.

(Breakout Group Discussant)

As a result of the breakout groups and reconvened forum, a number of Candidate Outcome Indicators for 'quality' emerged. These were discussed as being useful for the broad evaluation of telehealth. The candidate outcome indicators for quality were:

- quality of life
- health status
- quality of telehealth encounter (including patient and provider perception, satisfaction and waiting times)
- degree of integration and coordination of care / continuity of care
- quality of technology
- standards / policies (which are impacted by alternatives, type of services, complexity and phase of development)
- public health surveillance and protection
- quality of care and quality of service
- self-reported health status
- reduced burden of illness / injury
- waiting times
- patient satisfaction

[Subsequent to the Workshop, it has been recognized that some of these may not be indicators and duplication between these proposed indicators may exist. The investigation team will work to resolve these conflicts when preparing the Candidate Outcome Indicators for the consensus process].

#### 2.3.2 Outcome Indicators of 'Access'

There was general agreement amongst participants with the definition of access provided by Bashshur<sup>6</sup>. Thus access is considered:

The relative ease or difficulty in obtaining health services.

Bashshur went on to describe that a more detailed interpretation of 'access' could differ, based upon the perspective of the group involved. Thus, from the clients' perspective, access refers to the extent to which they face geographic, economic, architectural, cultural, and social barriers to the needed care. In contrast, for providers (in both remote and central sites), access relates to convenience, opportunity, cost, and workload. Finally, if considered from a societal and rural perspective, enhanced access to care increases overall satisfaction with life, and thus improves overall quality of life.

Access is an equity issue, a cultural issue and a relative issue.

(Workshop Participant)

As a result of the breakout groups and reconvened forum, a number of Candidate Outcome Indicators for 'access' emerged. Again, these were discussed and were considered useful for the broad evaluation of telehealth. The candidate outcome indicators for access were:

- wait times
- utilisation of health services
- availability (includes: technology, infrastructure, resources and acceptable alternatives)
- rate of utilisation
- timeliness
- public expectations and perceptions

[Subsequent to the Workshop, it has been recognized that some of these may not be indicators and duplication between these proposed indicators may exist. The investigation team will work to resolve these conflicts when preparing the Candidate Outcome Indicators for the consensus process].

#### 2.4 Recommendations

- The definitions and indicators defined above need to be subjected to either a Delphi or web-based consensus process to reflect the views from the broader telehealth community. [As seen in the NTOIP Information document, a web-based consensus process has been planned. The consultation process is now underway, based upon the content of this document].
- In completing the above, it would be prudent to ultimately select only 2 or 3 indicators for quality and access that can be agreed upon by the broader telehealth community.

#### 3. Acceptability and Cost

#### **Key Points:**

- Acceptability and costing estimates will change over time to reflect what is important in the present moment.
- For cost considerations, take the societal perspective.
- Tailor costing estimates to the needs of decision-makers.
- Consistent terminology is needed for Acceptability and Cost.
- Compromise between academic quality and immediate access to interpreted information must be sought.

#### 3.1 Introduction

Theme 2 of the NTOIP Workshop focused on acceptability and cost. The question for Theme 2 was:

Which Specific Outcome Indicators / Measures are Most Suitable for Broad Evaluation of Telehealth Applications for Acceptability and Cost?

#### 3.2 Presentations

Two presentations explored this theme from both a practical and theoretical perspective. The first presentation detailed how research in telehealth must change to incorporate new models, new philosophies, and transform approaches to better evaluate e-health applications in regards to acceptability. The second presentation provided an introduction to a developing web-based costing tool that models expenses for equipment, network rental, staffing, network usage, and bridging / gateway usage, and other costs.

## 3.2.1 Is Measuring Acceptability of Value, and If So How Do We Really Measure It? Nancy Lefebre, Saint Elizabeth Health Care.

The literature on satisfaction or acceptability states that: (1) the range of satisfaction measured is broad, (2) focuses on users of telehealth, (3) is not always exclusively measuring satisfaction, (4) is lacking clarity regarding what is actually being measured, and (5) that perceptions / attitudes focus on technology, privacy / confidentially, feelings and experience, timeliness and convenience, and preference.

The present journey of e-health research will go in either of two directions from where it is now. The first direction will lead e-health interventions to exist merely as an auxiliary service to more dominant forms of care. The second direction will allow e-health to meet its destiny and renew our health care system. To focus on the latter research arm, requires a new philosophy, a new model and a transformed approach. This further means that e-health research cannot be carried out in isolation of the rest of the health and human system.

This transformed approach to care delivery gives rise to the question: How does one measure new things and what will be the new indicators of acceptability and satisfaction? For example, in the aviation industry the satisfaction indicator in the past was safety. In today's world, however, safety is a given and the new indicator for satisfaction is price. The challenge is to determine today what will be the measures that will reflect what is relevant for the transformation of tomorrow.

To move from good to great e-health research, we need to evaluate not the change itself (for example, the process), but the results of the change (for example, the outcomes). In addition, we need to include consumers, clients, patients and users in the evaluation and evolution of e-health in general.

The Web of Wisdom Model (WOW Model) developed by Saint Elizabeth Health Care embodies the principles of transformative change in the delivery of health care. As a result new measures of acceptability need to be applied within the evaluation of this e-health initiative. Traditionally, one might look at improved access to health care and the satisfaction with the technology itself, however within this transformation new indicators for acceptability and satisfaction would include client empowerment, knowledge translation, capacity building, customization of care, and the meeting of clients expectations and needs such as feeling of comfort and security with their care anytime, anywhere.

It is also concluded that we need to measure satisfaction with care and delivery - anytime and anywhere possible.

## 3.2.2 Outcome Indicators: A Practical Web-based Costing Tool. Sharlene Stayberg, Alberta Health and Wellness.

In the next four years, Alberta will invest \$21 million dollars to establish an e-health network. The network will have sites in: 140 Regional Health Authorities, 9 Alberta Cancer Boards, 13 Alberta Mental Health Boards, 2 Alberta Health and Wellness Divisions, 12 planned Health Authority sites, 25 ultrasound sites, 23 First Nations and 12 Non-Health Authority systems. A total number of 236 sites will form the Alberta network.

Alberta Health and Wellness (AHW) developed a web-based costing tool that will be used to estimate the costs, and support decisions on what to charge for use. Currently, the costing tool only looks at costs of the network and excludes all benefits.

The four main limitations of the AHW Costing Tool include: 1) presently, the costing tool is a prototype and an operational tool (does not provide complete analysis), 2) it only looks at costs (excludes benefits such as travel costs avoided), 3) it is still based on the 80/20 rule (not yet full costs) and, 4) the validation process is not completed - the initial focus was on education and administration costs and the perspective is from the Health Authorities.

The five costing elements that are included in the AHW Costing Tool (both fixed and variable) are: equipment, network rental, staffing, network usage, and bridging/gateway costs. Excluded from the tool are: capital investment costs, administration overhead, any costs that fall beyond the telehealth department (for example, at the hospital administration level), and costs associated with clinical staff.

The main challenges regarding the development and application of cost indicators are: 1) there is no single economic model that is widely accepted and used, and 2) the costing tools (such as the AHW Costing Tool) need to support calculation of costs regardless of the local staffing situation and financial systems.

The next steps for improving the AHW Costing Tool will be to enhance the clinical application estimation (such as estimation of clinician salaries), and to compare costing methodologies with other Alberta systems. Other improvements will include validation of the tool, both within Alberta Health and Wellness and abroad, and to incorporation of other work to ultimately support development of new business models for telehealth.

#### 3.3 Group Discussion

Which Specific Outcome Indicators / Measures are Most Suitable for Broad Evaluation of Telehealth Applications for Acceptability and Cost?

#### 3.3.1 Outcome Indicators of "Acceptability"

One breakout group was able to provide a framework for acceptability. It was assessed during the workshop from the perspective of a patient and a provider, and was considered to have value. This framework is detailed in Figure 3 below.

#### Figure 3: Components of a Framework for Acceptability

When developing the components of a framework for acceptability, each question must be evaluated from the perspective of several users (such as patient, or public health nurse) regardless of geographic locale.

- 1. What are your expectations?
- 2. What are your needs?
- 3. What are the correlations between your expectations and reality?
- 4. How is telehealth customized to your situation?

When answering these questions, we need to be aware of the context of the service and how telehealth compared to the traditional form of care. [Assuming a comparable service existed prior to telehealth].

There was much discussion around the use of the term 'satisfaction' when defining 'acceptability'. Many members felt that the word 'satisfaction' contained too much baggage, and should either be downplayed or removed from the definition of acceptability. The terms 'satisfaction' and 'acceptability' tend to be used interchangeably. Thus, there is a need for consistency in terminology. Furthermore, it was noted by one participant that there are degrees or levels of acceptability.

The working definition of acceptability was:

The degree to which patients, clinicians, or others are satisfied with a service or willing to use it.

(IOM Model<sup>2</sup>)

One breakout group suggested taking note of the Webster's definition of acceptability, which makes no reference to the term 'satisfaction'. The Webster's Dictionary definition of acceptability is:

To accept, to take, to receive willingly, to be able or design to take or hold, to give admittance of approval, to make a favourable response, to receive favourably something offered.

(Webster's Dictionary<sup>10</sup>)

Therefore, one possible definition for acceptability could be:

The degree to which patients, clinicians, or others are comfortable or at ease with a service and / or willing to use it.

(NTOIP Combined definition)

It was noted by one breakout group that IOM moved away from 'satisfaction' and used the term 'acceptability'. It was further noted that there was a facile use of satisfaction scales. For example, we currently ask, "were your expectations met?" without first asking, "what were your expectations?" The latter is viewed as a better question, as what the former measures is unknown. This same group also noted the need to understand the level of perspective when addressing acceptability issues (such as patient, provider, or system perspectives), and briefly touched on the still contentious question of using the term 'patient' versus 'client' when looking at acceptability.

Another breakout group noted that an important component of acceptability is "knowledge transfer" from health-care provider to clients (patients), as a means of empowerment. They emphasised this as an important component of acceptability. e-Health by it's very nature changes the dynamics between health-care provider and patient and as such, has a direct effect on patients feelings, experiences, and comfort levels with both the technology and the level of care provided. This group suggested that the concept of 'acceptability' be replaced with a concept called 'user perception and dynamics'.

Yet another group revealed that both readiness (community and provider willingness to shift or change from conventional ways) and capacity (such as the number of colleges and universities that offer training) are also an integral part of acceptability. Without either readiness or capacity, 'acceptability' of e-health cannot occur.

Telehealth research is on a journey..., which means that we need a new philosophy, a new model and a new transformed approach to measurement.

(From a Workshop Participant's Presentation)

It was again noted that research and measurement on outcomes of acceptability (among others) cannot be carried out in isolation from the rest of the healthcare and social systems. We need to be aware that initial steps in measuring new outcomes associated with e-health applications evolve over time to reflect what is important at the moment. Measures of acceptability five years ago are much different from today's measures.

To move from good to great evaluations requires that we not only evaluate the change itself, but the results of the change.

(From a Workshop Participant's Presentation)

As a result of the breakout groups and reconvened forum, a number of Candidate Outcome Indicators for 'acceptability' emerged, and were determined to be useful for the broad evaluation of telehealth. The Candidate Outcome Indicators for acceptability were:

- empowerment
- informativeness
- expectations
- number of trips avoided
- needs
- fit between expectations and reality
- ability to customize and adapt the service (from individual patients to a group of patients)
- shift or transfer from face-to-face consultations to telehealth (when both alternatives are available)
- rate of utilisation
- base line utilisation rates (for telehealth, number of new users, capacity and training).
- adoption or diffusion rates
- number of new users
- capacity (training)

- number of agencies and funders funding research
- user preference (e-health verses traditional face-to-face encounters)

[Subsequent to the Workshop, it has been recognized that some of these may not be indicators and duplication between these proposed indicators may exist. The investigation team will work to resolve these conflicts when preparing the Candidate Outcome Indicators for the consensus process].

In addition to the COI's for acceptability discussed above, other perspectives and comments were raised during the reconvened session:

- People's expectations will directly affect acceptability outcomes.
- Different cultures have different needs acceptability must be context specific.
- We need to measure the results as well as the change itself this was a common theme throughout the discussion on acceptability.

One discussant commented that the challenge we face is to:

Develop an evaluation framework that works in theory and in practice.

(Breakout Group Participant)

#### 3.3.2 Outcome Indicators of "Cost"

General agreement arose around the importance of clearly describing the **opportunity cost** of any telehealth / e-health intervention when considering cost indicators. This significant form of cost is often overlooked. "Opportunity cost" is defined as the highest valued alternative forgone by following one course of action<sup>11</sup>.

One group specifically highlighted the related, but quite distinct issues of cost versus value. For example, "value" may be highly subjective and personalised and may change over time. In contrast "cost", although containing non-monetary aspects, can be clearly defined and measured. Arising from this discussion was concern that there is an urgent need to establish a 'value-based' case for telehealth, rather than solely a 'cost-based' case. This will require developing new indicators for value. [And convincing decision and policy-makers of the merit of this approach].

It is equally important to clearly state what costing elements are included and excluded in the analysis. Many studies that examine the costs of telehealth interventions do not clearly state which monetary, non-monetary, and fixed and / or variable costs are being examined. One participant suggested relating issues of cost to "facilitating and constraining factors", and that costing analysis must also pay particular attention to identifying the "winners and losers". For example, e-health patients may pay less in travel costs but the benefit of these cost savings are not passed on to other sectors of the economy (such as the transportation sector). Hence, it is important to keep the broader societal perspective in mind when analyzing costs – as cost savings in one sector will have ramifications in another sector(s) of the economy.

The concept of "winners and losers" was illustrated by the following example provided by one of the Working Group participants:

Traditional psychiatric care in Northern Canada means that many psychiatrists, who service the North, fly up in their own planes. The psychiatrists are reimbursed 3 times the normal rate for travel. The extra money earned from the reimbursement is used to pay and service the planes. In addition, while the psychiatrists are up North they are also engaging in activities such as visiting friends and fishing. The introduction of telepsychiatry to Northern Communities has resulted in less personal visits by psychiatrists – having an adverse effect on the psychiatrists' reimbursement and all sectors that are

related to Northern outdoor activities. [Through e-health, the health system 'wins' with reduced travel costs; and the Northern community 'loses' through reduced income].

(Workshop Participant)

When deriving e-health cost estimates, participants noted that the purpose is important. If you are completing a comprehensive costing study, then researchers need to be thorough and time is of no issue. On the other hand, if the goal of the costing study is to influence decision makers, one needs to get the costing information out fast. Time is of the essence, and therefore the analysis may not be complete or of 'academic quality'. Another suggested a way to influence decision-makers would be to highlight e-health success stories (for example, improving health care access to under-serviced populations). [This again relates to the transformation of TOD, discussed in Section 7].

At the moment, costing of e-health feels very rough. We need to move for some standardization of costing in e-health and report it in the same way. It needs to be [simple], elegant, scientific, and accurate.

(Workshop Participant)

It was identified by some group members that there is no need to focus discussion on technology and related costs, because certain tools such as budget logs and travel claims could be used in the costing exercises.

As a result of the breakout groups and reconvened forum, a number of Candidate Outcome Indicators for 'cost' emerged. Once more, during discussion these were found to be useful for the broad evaluation of telehealth. The Candidate Outcome Indicators for cost were:

- transportation costs
- industry investment
- facilities / space
- equipment
- human resources
- communications costs (bridging costs)
- training / education
- facility maintenance
- capital and operating costs
- marketing (promotion costs)
- warranties

[Subsequent to the Workshop, it has been recognized that some of these may not be indicators and duplication between these proposed indicators may exist. The investigation team will work to resolve these conflicts when preparing the Candidate Outcome Indicators for the consensus process].

One Working Group also identified possible **measures**. The suggested measures, which would be a way of quantifying / qualifying / gauging a visible change or effect, were:

- medevacs
- patient travel
- escorted travel
- lost working time

Working Group members made other important comments concerning the decision-making process and costing data. These were noted as 'parking lot' issues or topics that should be reviewed and debated at a later date. The main parking lot issues that arose from this discussion were:

- e-Health decisions should be made on the best available evidence. That said, caution is necessary because individuals will often make biased decisions, founding them not on 'best evidence' but on the evidence or information that they 'like best'.
- How do you get societally based evidence in front of decision-makers?
- The e-health community needs to create awareness about e-health among members of the public. This may be done via social marketing. This approach needs to touch on two main issues: 1) communication and promotion and 2) reliable costing information that decision makers can use.

#### 3.4 Recommendations

- The identified definitions and indicators need to be subjected to a consensus process to reflect the views from the broader telehealth community. [As seen in the NTOIP Information document, a web- based consensus process has been planned. The consultation process is now underway, based upon the content of this document].
- In doing this, it would be prudent to ultimately select only 2 or 3 indicators for acceptability and cost that can be agreed upon by the broader telehealth community.

#### 4. Economic Evaluation

#### **Key Points:**

- Economic evaluations of e-health applications need to be conducted when it is possible to compare e-health with a conventional service.
- Decision makers need both qualitative (value judgments) and quantitative (cost) data on which to base decisions.
- Highlighting success stories may also be used to influence decision-making.
- Compromise between academic quality and immediate access to interpreted information must be sought.

#### 4.1 Introduction

Theme 3 of the NTOIP Workshop focused on the economic evaluation of telehealth. The question for Theme 3 was:

What Model is Best for Economic Analysis of e-Health Applications?

#### 4.2 Presentation

This presentation focused on the economic evaluation of telehealth applications, noting the pros and cons of various models.

## 4.2.1 Economic Analysis of Telemedicine. Arto Ohinmaa, University of Alberta.

Telehealth can decrease the need to travel for both the client and healthcare professional, and also offers a cheap and fast way of sending patient data and to do medical consultations. Economic justification should be possible in some settings.

Economic analysis, which is the comparison of input and output values, depends upon five common economic evaluation methods or models. The first is the simple cost description, or cost analysis where one or more alternative interventions are compared, but the outcomes of the interventions are not measured or compared. The second method is the cost minimization analysis, where the 'effectiveness' of the alternatives is assumed to be the same and only the costs vary: the most cost saving alternative is identified. A third economic model is cost-benefit analysis, where the outcomes of the interventions being compared are 'valued' in monetary terms. This model provides for good comparability within the decision-making process since, in principle, all societal programs can be compared, not just those amongst healthcare. The fourth economic evaluation method is the cost-effectiveness model. When performing a costeffectiveness analysis the cost / effectiveness ratio is derived as cost per unit of outcome for each alternative, and there is no comparison between measures and there are no common metrics. The final common economic evaluation method is the cost-utility model where the cost / QALY (Quality Adjusted Life Year) ratio is derived and compared between alternative interventions. This economic evaluation technique has methodological problems, but is preferred by most economists.

What is the quality of the evidence that exists on economic evaluation of e-health applications? A recent study <sup>12</sup> assessed the quality of the literature by looking at 609 papers dealing with the evaluation of telehealth. Out of the 609 studies, 124 dealing with assessment of telehealth were

retrieved for closer inspection. From these, 44 papers were judged to meet the selection criteria. Four (4) other publications were identified through references cited, giving a total of 48 papers addressing 46 separate studies. Of these articles 23 reported clinical or administrative outcomes, 16 were mainly economic analyses, and 9 included both economic and clinical or administrative details. Some kind of economic analysis was included in 25 (52 %) of the papers and all studies were cost analyses (including cost-minimization analysis studies).

The quality of the economic analysis was assessed by the 10-step criteria, as defined by Drummond  $et\ al^{13}$ . About 56% of studies had good or moderate economic quality (score 5 or more, as defined by Drummond  $et\ al$ ). Of the studies reviewed, 60% of the articles valued the costs credibly and discussed the economic study results. 50% of the articles identified costs and affects in a satisfactory way, 43% of the articles measured effectiveness, 30% timing and uncertainty, and 13% performed an incremental analysis.

It can be stated that the quality of economic studies has improved over time. However, many studies do not give enough information about the processes for cost (and effectiveness) measurement and evaluation. There were also significant methodological mistakes apparent in both of these areas. Further, telehealth evaluations often fail to compare costs and effectiveness with conventional alternatives, reducing the value of the results for decision-making. Overall, there are few good quality studies, but some do exist in the areas of dermatology, geriatrics, hospital referrals, mental health, and one sleep study.

#### 4.3 Group Discussion

#### What model is best for economic analysis of e-health applications?

For this session the participants did not breakout into groups, but discussed the topic in a large group format, due to the complexity of the subject matter and the lack of economists who could disperse amongst breakout groups to comment on the issues raised (only two economists participated in the NTOIP Workshop).

### 4.3.1 Which Economic Evaluation Methodology is Best for Evaluating e-Health Interventions?

Choosing the right economic evaluation technique (whether it be cost-effectiveness, cost-benefit, or cost minimization analysis) will vary depending on:

- Which sector you are from
- Resource allocations (both time and money)
- The level of detail one needs

The telehealth community is at a cross roads: if there is little economic evaluation information gathered now, then decision makers will not have the pertinent information on which to develop telehealth policy. This in turn will have a direct impact on outcome themes such as quality, access, acceptability, and costs. It was also noted that when completing economic evaluations, it is important to keep in mind the perspective of the audience at which the evaluation is directed. There was general agreement with the comment of one participant:

Currently, there is no comprehensive and complete cost / benefit analysis model for telehealth applications that could be used as a guide.

(Workshop Participant)

It was identified that skill and resources are needed for sound economic evaluations. Most e-health practitioners do not have the economic skills required to complete an economic evaluation.

and thus must resort to acquiring external economic evaluation expertise. This may increase both the time and the resources needed to do such an evaluation.

The participants noted that it is the responsibility of e-health researchers, to provide decision-makers with as much information as possible. That said, good quality evaluation of new technologies (e-health or otherwise) is extremely difficult to do. If you want to do a comprehensive study, you need the time (and funds) to do it. However, as one working group discussant noted:

If you want to influence decision-makers, you need to get good quality information out fast, and accept the fact that the information may not be complete or of 'academic' quality.

(Workshop Participant)

Participants agreed that information that is less than academic quality can still be useful if it is interpreted appropriately, distributed rapidly, and to the right audience.

The points raised above led to a discussion on how to influence decision-makers. One participant identified the value of using "success stories", while another participant added that it is important to first identify the decision makers and the levels they are at in order to understand what information will influence them. Therefore, it is crucial to know how government operates, how various government departments are structured, and how arguments need to be customised for particular departments.

The discussion on value continued at this time, with the group struggling with the notion of 'value' as well as how to measure it. It was again reiterated that value is a subjective term and some decisions are made on value judgments rather than on hard evidence. How do you place a value on information used in decision-making, decreased travel costs, and benefits? No solution was provided, other than agreement that value judgments are needed to supplement the hard data.

Another previously noted issue was raised again. That is, even though e-health is new, we need to take the time to compare such applications to conventional services. However, it was stated that there are often no conventional services against which to compare an e-health application – particularly in rural and remote areas. [This premise is open to debate. For example, a teledermatology clinic to a remote location that previously had none might be claimed to be entirely 'new'. Yet it might also be argued that the population in that remote location always had the ability to pursue the existing service route, no matter how inefficient or awkward it might have been (e.g. mail referral; prolonged wait time for specialist appointment; extensive, costly, difficult, and repeated travel to distant clinics)].

During the discussion around which economic evaluation method was the most appropriate to use, it was noted by some group members that highlighting success stories might be beneficial to decision-makers. This was reminiscent of the expressed desire to reformulate the TOD framework, and continued identification of success stories by participants furthered the development of the Minimum Influential Dataset Activity (MIDA), as detailed in section 7.

#### 4.4 Recommendations

- In order to inform and influence decision- and policy-makers, information of less than academic quality must be analysed and interpreted fairly, and the results disseminated rapidly to the appropriate target groups.
- Because the economic skills required by e-health evaluators are not present or readily available, emphasis should be placed on establishing user-friendly economic methods and tools that could be broadly used.

#### 5. Dissemination of Outcome Indicators

#### **Key Points:**

- "If you don't have the time to do it right the first time, when will you find the time to do it over?"
- Document and disseminate all lessons learned.
- Communicate the process as well as the results of this Workshop and NTOIP.
- Develop consensus using a Delphi or web-based consensus process.
- 'Measure the right thing, and measure the thing right'.
- Focus on 'what is measurable, and what is meaningful'

#### 5.1 Introduction

Theme 4 of the NTOIP Workshop focused on the dissemination of outcome indicators of telehealth. The question for Theme 4 was:

How Must Identified and Defined Outcome Indicators be Disseminated and Presented to Ensure Acceptance and Adoption by the Broader Telehealth Community?

#### 5.2 Presentations

The last two presentations focused on the theme of dissemination of indicators. The first introduced the concept of change as a way of moving from one status quo through change to a new status quo. Thereafter, the final presentation explored why it is important to support adoption of consistent and defined outcome indicators. The arguments and rationale developed will become a tool with which to gain support from the broader telehealth community as the NTOIP process moves forward.

## 5.2.1 What Makes Us Ready and Willing to Accept New Paradigms? Penny Jennett, University of Calgary.

The presentation began with a discussion around "readiness", moved to a discussion of desirable characteristics of outcome indicators and criteria for measures: then concluded with a challenge.

Change, as defined by Lewin<sup>14, 15</sup>, requires moving from the status quo (frozen state), unfreezing, and moving to a new status quo. A state of readiness is required to begin the "unfreezing" process. Individuals, organizations, communities, and society are often at different stages of readiness. Readiness to change consists of five stages: pre-contemplation (no thought of change), contemplation (thinking about change), decision / determination stage (making a plan to change), action (implementation), and maintenance (continuation of desirable) <sup>16</sup>. How ready is the telehealth community to adopt a core standardized outcome definitions, measures, and tools <sup>17</sup>? The community needs to value the relative advantage of moving towards this goal, and to be convinced of its merit. Opinion leaders, experts change agents, and change aids are required to make this happen. This Workshop provides an opportunity for participants from across Canada, (opinion leaders, experts, and change agents), to discuss the value and merits of consensus in this area.

Ten desirable characteristics for indicators were shared with participants <sup>18, 19</sup>. These include: reliable; valid; responsive and relative; interpretable; feasible; flexible; documented; important and meaningful; spanning control/time of impact; reasonable; and linked to goal and targets. Criteria

and questions for a structured review of an outcome measure were shared<sup>1</sup>. The challenge with respect to accepting a new paradigm for indicators and measurement is to ensure that we measure the right thing and measure the thing right<sup>18</sup>. We also need to decide if findings are for the purpose of awareness, informing, influencing, or persuading. Each purpose may require different characteristics, questions, and / or criteria. There always remains the balance between psychometric adequacy, and political or administrative need: what is measurable, and what is meaningful.

## 5.2.2 Why Should We Adopt Consistent and Defined Outcome Indicators? Richard E Scott, University of Calgary.

In 1997, the National Forum on Health in Canada indicated the need to adopt an evidence-based approach to our health system. Evidence-based was described as 'the systematic application of the *best available evidence* to the evaluation of options and to decision making in clinical, management, and policy settings'.

Six years later, healthcare managers and policy makers are making major decisions about the allocation of already scarce healthcare resources for e-health solutions. But the valid and consistent data essential to making the correct decisions is still lacking. There is a need for common yardsticks and common tools in order to avoid making poor decisions around implementation and integration of e-health.

To address this need, specific outcome indicators must be identified, defined, tested, transferred into practice, and consistently applied and used. In pursuing this goal, Pareto's principle (or the '80/20 rule') should be noted – there is urgency in addressing the goal of common and consistent outcome indicators, but perfection must not become the goal itself. In this way a small number (core set) of outcomes could be measured in all telehealth and e-health activities (together with other project / program specific outcomes), permitting the rapid growth of a body of consistently measured data to build the needed evidence base.

Implementation of common indicators will benefit many stakeholders, including consumers, academics, professionals, private industry, the public, and Canada (Figure 3). 'Good Evidence' will permit the right choices to be made, and lead us in the right direction for additional benefits, including the final outcome of a 'Healthy Population', as well as stimulating the economy, developing proven solutions, and making Canada a world leader in the development and application of e-health outcomes.

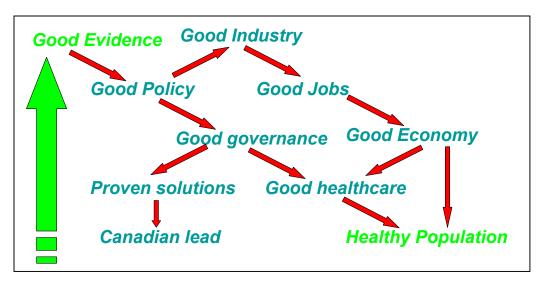


Figure 3. Additional benefits of using consistent outcome indicators to build good evidence and a healthy population

Common and consistent outcome indicators also provide value for politicians, decision-makers, and policy-makers who require high-level aggregate data in order to compare or defend investment in e-health. At the same time the general public would benefit from common indicators, as they require high-level summative data in order to make judgments, and political decisions<sup>18</sup>.

In order to influence policy, it is necessary to provide sound evidence on a consistent basis – and the time is NOW. A valuable quote ended the presentation that dealt with the need to take the time required to perform sound research:

"If you don't have the time to do it right the first time ... when will you find the time to do it over" 20.

#### 5.3 Group Discussion

How must identified and defined outcome indicators be disseminated and presented to ensure acceptance and adoption by the broader telehealth community?

#### 5.3.1 Document Lessons Learned and Disseminate

The group unanimously agreed that as we move from telehealth practice to telehealth policy, it becomes very important to document lessons learned, and to broadly disseminate them in both passive and pro-active ways. This will allow others to benefit from our experiences – both positive and negative. One Workshop participant noted that currently, there is little done in the area of documenting the flood of lessons learned within telehealth. For example, in Atlantic Canada 36 telehealth studies / projects have been performed, but only 3 have been documented.

Dissemination of *lessons learned*, as well as the *results*, leads to awareness, which in turn leads to acceptance or endorsement, and ultimately to adoption. As we move from each stage along the adoption continuum, we must engage all players within the telehealth arena. Doing so will ensure transparency and will allow ease of movement from awareness to acceptance and eventually to the adoption stage. The group agreed that one method of communicating the results and process of the NTOIP Workshop would be to develop a "heads-up" one-pager which could be circulated to government officials, Canadian Institute for Health Information (CIHI), Canadian Society of Telehealth (CST), and other interested parties.

We need to Align, Simplify, and Act - ASA.

(Workshop Participant)

#### 5.3.2 Consensus

The group expressed the view that we need to be prepared for lack of consensus now and in the future. As a group, we may be able to agree on a few Candidate Outcome Indicators, but this consensus may be lost when these indicators are viewed and critiqued by a wider audience as part of any consensus building process. This is to be expected, as outcome indicators are directly affected by: differing perspectives of those who use them; lack of consistent indicator definitions, and different degrees and levels of outcome indicators. *When this happens, we should not get discouraged.* The group also noted that the telehealth / e-health is a rapidly changing field, and that we need to remain flexible and adapt to the constant evolutions that are expected to occur. *To succeed we need to remain balanced, focus on alignment, keep the issues simple, and move into action in order to advance from where we are now.* 

To get agreement on the outcome indicators we need to create awareness and communicate our work to date on indicators.

(Workshop Participant)

A number of group members indicated that one way in which to communicate our work on outcome indicators, and to gain consensus, would be to disseminate the process and results on the web. This will help to increase awareness among other groups and organisations such as CIHI (who we want to engage, as they have expertise in this area) and CST (a non-government organisation that has strong influence in the telehealth segment of the e-health arena). It was noted that what is placed on the web will represent a very iterative process. The outcome indicators research is a work in progress, is dynamic, and is expected to change over time. One participant suggested that we might want to enter into a CIHI-CST partnership that could provide great value in terms of strengthening our work on outcome indicators.

The group further discussed the issue of informing opinion leaders and change agents, in addition to organisations such as CIHI and CST. Group members suggested that organizations like the Health Council, Health Canada, Canada Health Infoway Inc., and Government Leaders should be made aware of the outcome indicator project using the heads-up one-pager mentioned above.

A number of participants suggested a way of marketing this work would be to clearly answer and define issues such as:

- · What was the impact?
- What was the outcome?
- Provide a value statement to get buy-in.
- Use terms such as "informed decision making" and "benchmarking" key words and hot phrases that everyone will recognise.
- Information that we are providing will complement existing evaluation efforts.
- Awareness that social and ethical value assessments are very difficult to measure and define
- Identify indicators that are specific and useful to telehealth.
- Three objectives of this research need to be articulated:
  - o Improve the health of Canadians
  - o Increase economic development
  - o Create the evidence for evidence-based decision making.

# 5.4 Recommendations

 What we have accomplished to date, and where we intend on going in the future, must be communicated as broadly as possible.

# 6. Accepted NTOIP Definitions and Candidate Outcome Indicators

#### 6.1 Introduction

Through the breakout sessions and the reconvened forum, the NTOIP Workshop participants have come to consensus on a number of definitions and have identified a variety of Candidate Outcome Indicators. For easy reference, these definitions and Candidate Outcome Indicators are summarized in this section \*.

[Subsequent to the Workshop, it has been recognized that some of these may not be indicators and duplication between these proposed indicators may exist. The investigation team will work to resolve these conflicts when preparing the Candidate Outcome Indicators for the consensus process].

# 6.2 Generic Outcome Definitions<sup>1</sup>

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

**'e-Health Outcome Indicator'.** 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).

**'e-Health Outcome Measure'.** 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 Hospitalizations; Length of Stay; Distance to Nearest Facility; Rurality).

'e-Health Outcome Tool'. The specific instrument used to collect quantitative or qualitative data for any single outcome measure. (Examples 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)).

# 6.3 Quality - Definitions and Candidate Outcome Indicators

'Quality'. Those relevant characteristics, other than time, which influence the experience obtained from the use of telehealth<sup>1</sup>.

## Candidate Outcome Indicators for quality are:

- quality of life
- health status
- quality of telehealth encounter (including patient and provider perception, satisfaction and waiting times)
- degree of integration and coordination of care / continuity of care
- quality of technology
- standards / policies (which are impacted by alternatives, type of services, complexity and phase of development)
- public health surveillance and protection

<sup>\*</sup> All definitions have been referenced earlier in this document.

- quality of care and quality of service
- self-reported health status
- reduced burden of illness / injury
- waiting times
- patient satisfaction

## 6.4 Access - Definitions and Candidate Outcome Indicators

'Access'. The relative ease or difficulty in obtaining health services<sup>6</sup>.

## Candidate Outcome Indicators for access are:

- wait times
- utilisation of health services
- availability (includes: technology, infrastructure, resources, and acceptable alternatives)
- rate of utilisation
- timeliness
- public expectations and perceptions

# 6.5 Acceptability - Definitions and Candidate Outcome Indicators

'Acceptability'. The degree to which patients, clinicians or others are comfortable or at ease with a service and / or willing to use it. (NTOIP combined definition<sup>2,10</sup>).

# Candidate Outcome Indicators for acceptability are:

- empowerment
- informativeness
- expectations
- number of trips avoided
- needs
- fit between expectations and reality
- ability to customize and adapt the service (from individual patients to a group of patients)
- shift or transfer from face-to-face consultations to telehealth (when both alternatives are available)
- rate of utilisation
- base line utilisation rates (for telehealth, number of new users, capacity and training).
- adoption or diffusion rates
- number of new users
- capacity (training)
- number of agencies and funders funding research
- user preference (e-health verses traditional face-to-face encounters)

# 6.6 Cost - Definitions and Candidate Outcome Indicators

'Opportunity cost' is defined as the highest valued alternative forgone by following one course of action<sup>11</sup>.

#### **Candidate Outcome Indicators for cost** are:

transportation costs

- industry investment facilities / space equipment

- human resources
- communications costs (bridging costs)
- training / education
- facility maintenance
- capital and operating costs marketing (promotion costs)
- warranties

# 7. Evolution of the Minimum Influential Dataset (MID)

# **Key Points:**

- There was the desire to move TOD away from a conceptual framework to a living, working tool; this became known as the Minimum Influential Dataset (MID).
- The Minimum Influential Dataset needs to be populated with real life examples if it is to be a useful tool in influencing decision-making.

#### 7.1 Introduction

The NTOIP Workshop participants accepted the TOD Framework as a conceptual model. But there was an expressed desire, evident throughout the Workshop, to reformulate the conceptual TOD framework into a living / working tool. Efforts to reformulate the TOD framework into an applied tool ultimately resulted in the development of what became known as the "Minimum Influential Dataset" activity (or MID).

# 7.2 Development of the Minimum Influential Dataset Activity

As the NTOIP Working Group participants grappled with the best means of influencing policy makers, the follow questions arose:

- Who are the players of influence?
- How do we influence the decision-making process?
- What experiences and / or examples do the Working Group participants have to share regarding e-health success stories?

In addressing the questions above, the NTOIP members <u>began</u> to identify the important players of influence and the experiences they had had in influencing policy. As this was a diversion from the original Workshop program, members were asked to take some time to order their thoughts around identifying the policy makers and which health care values are important to them using a swiftly developed tool (Appendix 5). The major players of influence identified by the group were: the general public, policy-makers, decision-makers, funders, service providers, and the media. The health values identified and agreed upon by the group were: need, equity, cost, quality, access, impact, outcome, and miscellaneous.

Participants were subsequently polled to identify which boxes they had checked in the Minimal Influential Dataset tool. The results of this exercise can be seen in Table 1, where the numbers in the boxes can be considered as a crude representation of the relative importance of the rubric at any point of intersection. Thereafter, participants were asked to relay any success stories that they knew of, or were part of, regarding implementing e-health. The descriptions were then collated within the framework developed by participants, creating Table 2. The concept and content seen in Table 2 became known as MID (Minimum Influential Dataset).

MID defines both the actors (people of influence) and important health values (such as equity and cost), while illustrating real-life examples of how telehealth applications have affected selected individuals / groups in positive ways.

Table 1: Results of the Initial Minimum Influential Dataset Development Process

Health	General	Policy	Decision	Funders	Service	Media
Values	Public	Maker	Maker		Provider	
		(Planners)	(Politician or			
			Manager)			
Need	10	8	9	8	4	3
Equity	3	10	3	3	2	3
Cost	10	11*	11*	11*	5	4
Quality	11*	10	6	3	12*	1
Access	11*	11*	5	6	6	5
Impact	4	10	7	10	9	10
Outcomes	4	8	4	4	10	4
Mics/others						

**NOTE:** The numbers in the chart indicate the number of individuals who thought that the rubric at any given point of intersection was important. The star (\*) represents those quadrants that were voted as significant (11 or more 'votes').

Table 2 illustrates through real life examples how telehealth has affected a variety of health related issues. The intent is to ask the broader telehealth community to fully populate the table. The columns identify the primary actors involved, and the rows detail the values that individuals and society place on health care services. In addition, the decision to support telehealth (or the issue(s) surrounding telehealth adoption) has also been identified.

MID will need to be further populated with additional real-life examples. The group agreed that MID should to be sent out to a wider audience for critique.

Ask the telehealth community to populate the model with examples of what they already use, and try to align this with other activities that are happening in Canada.

(Working Group Participant).

## 7.3 Recommendations

MID, as developed by the group, needs to be populated with more real-life examples.
 The broader telehealth community should be given the opportunity to populate MID and to revise the actors of influence / health values.

Table 2: Minimum Influential Dataset Activity (MIDA)

	General Public	Policy Maker (Planner)	Decision Maker (Politician or Manager)	Funder	Service Provider	Media
Need	Decision to Support e-Health: Community readiness, awareness of e-health as an option, meets my needs, primary and specialty care when it is needed, unmet needs. Example: Providing services not before available in a patient's community.	Decision to Support e-Health: Unmet need, address inadequacies in service delivery, attention to minorities and vulnerable members of society. Example: Canada Health Act, CHIPP (program advisory board-strategic planning).	Decision to Support e-Health: Healthcare system readiness.	Decision to Support e-Health: Project proposals demonstrate need. Example: Proposal contains demographic detail and needs assessment results. Reports, briefs etc from policy contains: issues to be addressed, identification of models that work if possible, HISP results.	Decision to Support e-Health: Provider readiness, unmet need, improves current practice.	Decision to Support e-Health: Compelling story, hot topic, and public interest.
Equity		Decision to Support e-Health: Rural access and sustainability of services.		Decision to Support e-Health: To address regional disparities and to look for a broader reach. Example: Work plan addresses accessibility and identify indicators to prove concept.		
Cost	Decision to Support e-Health: Decrease Travel costs, host wages, other costs (child care), lost wages,	Decision to Support e-Health: Cost to health care system, cost within budget allocation, high impact such as short timelines, complement current strategic plan, understanding change management.	Decision to Support e-Health: Cost savings to health care sector, impact on health care delivery. Example: Decrease in cost of patient travel and decrease in LOS.	Decision to Support e-Health: Perception and reality of improved service at lower or same cost, context, competing demands, high impact at low cost, ROI with fit to priority areas at acceptable risk and with long run sustainability, sustainable program, program/project has adequate money to deliver, cost effectiveness within work plan, policy makers have identified cost issues to be addressed. Example: Capacity to do the work and	Decision to Support e-Health: Within existing allocations, spending no more.	

	General Public	Policy Maker (Planner)	Decision Maker (Politician or Manager)	Funder	Service Provider	Media
				adequate budget and work plan. Original business case for telehealth in Alberta, management board report (included compelling stories, when the request for information was strictly data, which was very well received).		
Quality	Decision to Support e-Health: Service, as good as or better than I have now, sustainability Example: Story – quality and access story specific to telenephrology between 2 sites. \$8000/year personal cost savings. With out e-health would not have renal dialysis service (access). Issue – people who are sensitive to PC or ICT technology will pick up the activities faster than others.				Decision to Support e-Health: Maintain standards, technical quality, access to specialist/ consult and education to enhance ability to care for clients, standards and best practices of care delivery. Example: e-Health initiatives - built in standards, best practices, improved knowledge and capacity building . NB VITAL (tele- cardiology), Tele IV (PACS) - story specific to service provider and quality (resulted in better diagnostic quality, eliminated lost films, quick access to second opinions and retention and recruitments of radiologists), competition between regions/cities for e- health capabilities may increase uptake and result in better quality and access). VIRTUAL LUNCH - introduction to telemental health in Alberta (via demos of technology, presentation of	

	General Public	Policy Maker (Planner)	Decision Maker (Politician or Manager)	Funder	Service Provider	Media
					evaluation information and standards used, outline services available i.e. could see a sub-specialist services if available), getting support from specialist during emergencies when you need it 24/7.	
Access	Decision to Support e-Health: Convenience (self and family), timeliness, speed, access to specialist without travel and other costs, decrease personal costs, availability (location, waiting time, hours open), connects me to a specialist faster and without travel costs and inconvenience, diagnose a "problem" quickly and easily. Example: Many people in northern communities do not have family practitioners – who have become huge and effective ambassadors for e-health (Kirkland Lake, local champions). Services in northern communities need to be cultural appropriate.	Decision to Support e-Health: Rural needs		Decision to Support e-Health: Improved health service access for citizens related to priority areas, serving under served populations, keep doctors happy by decreasing stress, isolation, rural areas.	Decision to Support e-Health: Increase access to clients with decrease travel costs and times.	
Impact	Decision to Support e-Health: Emergency care when it is needed. Example: Getting emergency care specialist at health centre.		Example: Good news here is what my government is doing for you.		Decision to Support e-Health: System reform (meet goal objectives).	Decision to Support e-Health: Compelling human-interest stories. Example: Introduction of new telehealth services in Alberta (i.e. Health Link and Cochlear implant speech therapy), VR News did a lengthy "spot" on Parry Sound's "go-live" that CNN has used over and over in presentations (video).
Outcome		Decision to Support e-Health: Outcomes pilot program (HISP). Example: Outcomes require proof of			Decision to Support e-Health: Maintain reasonable objectives, outcomes not sexy (?), impact level of care.	Decision to Support e-Health: Compelling stories and testimonials (saved lives!) – Outcomes

	General Public	Policy Maker (Planner)	Decision Maker (Politician or Manager)	Funder	Service Provider	Media
		concept.			Example: Improved outcomes of increased knowledge self management behaviours	(what are the alternatives?)
Other						

# 8. Overall Recommendations and Next Steps

This document details the presentations, discussions, and recommendations that were part of the NTOIP Workshop held in late June 2003. However, the report is not the final stage in the process. As noted, participants were adamant that the final report from the NTOIP Outcome Workshop must not be just a synthesis of the experiences and expertise shared by the participants, but must be widely shared. As a consequence, the recommendations identified by participants must be followed up through a series of logical 'next steps'.

Seven main recommendations have been identified from the proceeding text. The following summarises these recommendations, and identifies the specific 'next steps' that will be undertaken to move this body of work forward.

Recommendation 1: The conceptual TOD framework and generic outcome definitions should

be disseminated for broader critique.

**Next Steps**: Opportunities for further dissemination will be pursued in order to subject

them to the scrutiny of peers.

Recommendation 2:

Transformation of the original conceptual TOD framework into a practical

tool should be pursued.

**Next Steps**: The process initiated with the Minimal Influential Dataset activity will be

supported through the NTOIP website [www.ucalgary.ca/NTOIP] to

encourage continued development.

**Recommendation 3**: The identified definitions and indicators need to be subjected to a

consensus process to reflect the views from the broader telehealth

community.

**Next Steps**: The planned web-based consensus process will be pursued.

**Recommendation 4**: In completing the above, it would be prudent to ultimately select only 2 or

3 indicators for quality and access that can be agreed upon by the

broader telehealth community.

**Next Steps**: For each outcome theme, a limited number of candidate outcome

indicators (e.g. 2-5) will be selected by the broader telehealth

community through the consensus phase of NTOIP.

**Recommendation 5:** In order to inform and influence decision and policy-makers, information

of less than academic quality must be analysed and interpreted fairly, and the results disseminated rapidly to the appropriate target groups.

**Next Steps**: The broader telehealth community will be informed of this and

encouraged to understand the need for rapid response to decision- and

policy-maker needs, and the need to develop effective means of

extracting valid conclusions from available data.

**Recommendation 6** Because the economic skills required by e-health evaluators are not

present or readily available, emphasis should be placed on establishing user-friendly economic methods and tools that could be broadly used.

**Next Steps**: The broader telehealth community will be informed of this and

economists encouraged to respond to the identified need.

Recommendation 7:

What we have accomplished to date, and where we intend on going in the future, must be communicated as broadly as possible.

Next Steps:

i) The process and results of NTOIP will be disseminated via the web (NTOIP website [www.ucalgary.ca/NTOIP])

ii) The broader telehealth community will be informed of NTOIP, and will be encouraged to actively participate in the consensus process.

iii) A "heads-up" one-pager will be developed and distributed to opinion leaders, change agents, and the broader telehealth community. iv) Specific groups or organisations will be contacted and informed in

greater detail about NTOIP.

v) The possibility of formal partnership with established organisations will

be explored.

**Recommendation 8:** MID, as developed by the Workshop participants, needs to be populated

with more real-life examples. The broader telehealth community should be given the opportunity to populate MIDA and to revise the actors of

influence and health values.

**Next Steps**: MID will be placed on the NTOIP website as a distinct activity, and the

broader telehealth community invited to further populate the table.

# 9. Concluding Comments

The NTOIP Information Document<sup>1</sup> has stimulated great interest, and this Workshop – although a challenge - can be considered a success. It would seem that the issue of identifying, defining, and applying consistent outcomes in e-health evaluations is an issue whose time has come. The stage is set, and NTOIP is merely stimulating the process. In the end it is we, individually and collectively, as e-health proponents that will make it succeed or allow it to fail.

Many issues and topics were addressed during the NTOIP Workshop, and the sincerity, realistic determination, and valuable input of participants is clear from the content of this report and from the various 'key points', 'recommendations', and 'next steps' identified. Another way to gauge the tone and value of the workshop is to review the general opinion and overall experience of NTOIP Workshop participants. Comments and observations made by participants have been summed up below:

- We need to start somewhere. This is a valuable exercise and it is a good place to start.
- It is important to capture the wide variety of perspectives that existed in this Workshop, and such perspectives will be become even wider as we disseminate our work to the broader telehealth community.
- We need a focus that will help in gathering meaningful and useful data.
- There are multiple needs and multiple players, which means that we will need to manage our expectations.
- Aligning with other initiatives is important.
- Where there is a need, we should be promoting identification, definition, and adoption of an outcome indicator.
- We need to develop a consensus on which broader framework we should align with.
- Balance is paramount; telehealth is a unique community with varying needs and players.

As co-investigators for the study, and as colleagues, we extend our sincere thanks to all participants of the NTOIP Outcomes Workshop 2003 (Appendix 1), to the rapporteurs, and to the authors of this report. We also look forward to the future challenge of seeking a consensus from our colleagues in the broader telehealth community.

Together, we can .....

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# **Appendix 1: NTOIP Participants**

# **HTU Organizing Committee:**

Richard Scott – University of Calgary Bonnie Rush – University of Calgary Mone Palacios – University of Calgary

# Speakers:

Sandra Chatterton – Health Canada Penny Jennett – University of Calgary Nancy Lefebre – Saint Elizabeth Health Care Arto Ohinmaa – University of Alberta Richard Scott – University of Calgary Sharlene Stayberg – Alberta Health and Wellness

# Facilitators (F) and Rapporteurs (R):

Richard Scott (F) and Bonnie Rush (R) – Breakout Group 1 Marilynne Hebert (F) and Heidi Brandstadt (R) - Breakout Group 2 Tina McKinnon (F) and Maryann Yeo (R) - Breakout Group 3

# Other Participants (excluding speakers):

Pin Cai – University of Calgary
Jean Paul Fortin – University of Laval
Valerie Hagerman – New Brunswick Department of Health and Wellness
Robert Hanson – OHIH, Health Canada
John Hogenbirk – Laurentian University
ChrisAnn Ingram – Izaak Walton Killam Health Centre
Mone Palacios – University of Calgary
Lisa Sarsfield – NorthNetwork
Mo Watanabe – University of Calgary
Wang Xiaomin – Shandong Provincial Telemedicine Centre, China

# **Appendix 2: NTOIP Speaker Biographies**

# Sandra Chatterton - Senior Policy Advisor Health Canada

Sandra Chatterton is Senior Policy Advisor at the Office of Health and the Information Highway (OHIH), Health Canada. Her Federal career has included work in community health, social welfare policy, workplace education, labour policy and, currently, information technology and health care delivery.

Her experience in evaluation has included: leading the evaluations of three federal funding programs, developing performance measurement indicators of employee contribution to be tested by Treasury Board, and at the Office of Health and the Information Highway developing and implementing the Canada Health Infostructure Partnerships Program (CHIPP) Evaluation Framework. Currently at OHIH, she is responsible for managing the CHIPP project evaluation process, and will participate in the evaluation of CHIPP's outcomes and impact.

# Penny Jennett - Head, Health Telematics Unit University of Calgary

Dr. Penny Jennett, Head, Health Telematics Unit, Professor, Faculty of Medicine, University of Calgary is recognized internationally for her expertise in telehealth, e-health, health telematics / informatics, and medical education. She is President and Founding Member of the Canadian Society of Telehealth (CST), treasurer / member of the Board and Executive of Canadian Network for the Advancement of Research, Industry, and Education (CANARIE) Inc., and serves as Vice-Chair of the Board of Netera. She received the first Digital Group of Telehealth Companies "Award of Excellence" for her significant contributions to telehealth in Canada. The University of Calgary, Faculty of Medicine, Department of Community Health Sciences awarded her the "2<sup>nd</sup> Annual Golden Apple Award for Excellence in Graduate Science Education" for demonstrating an outstanding interest and participation in education and student issues. Dr. Jennett is Project Lead for the EU-Canada Collaborations in Health Telematics Initiative, and led national initiatives to build research capacity in rural / remote areas of Canada.

# Nancy Lefebre - Vice-President, Knowledge Saint Elizabeth Health Care

As Vice-President of knowledge, Nancy is leading the creation and transfer of wisdom throughout Saint Elizabeth Health Care, positioning the organization to become a knowledge leader in health care. Through the use and exploration of exciting technology solutions, Nancy is fast-tracking the cultivation and sharing of our talent.

Nancy has more than twenty years of experience in the North American health care sector, with a focus on community care. From direct care practice to management, as well as the development of new business, Nancy's enthusiasm, energy and commitment to community are evident in the roles she has held throughout her career. She achieves balance through the enjoyment of peaceful rural life with her young family.

# Arto Ohinmaa - Associate Professor University of Alberta

He received his Ph.D. in economics from the University of Oulu in Finland, and he has been Associate Professor in health economics at the Department of Public Health Sciences, University

of Alberta since summer 2001. He is Research Fellow in the Institute of Health Economics, Edmonton.

He has cooperated with health care districts and social security and health care research organizations. His research interests include assessment of the telemedicine, health-related quality of life measurement, health technology assessment, distribution of health and health care costs in the population, economic assessment of health care, and connection with assessment studies and policy decisions. He has written articles in the areas of assessment of telemedicine, health technology assessment, and health-related quality of life.

# Richard Scott - Associate Professor, Fulbright New Century Scholar Alumnus University of Calgary

Dr. Scott has over 18 years healthcare experience as an e-health researcher, Director of Research, and practicing clinical and forensic toxicologist and clinical chemist. He is examining the role of e-health in the globalisation of healthcare, and investigating policy and evaluation aspects impacting the implementation and integration of e-health globally. Currently he is pursuing development of a global e-health policy matrix model to encourage and facilitate policy relevant research in this area, and is developing an e-health specific business case model to encourage sustainability of e-health initiatives. In addition he has blended his experience in toxicology with e-health to spawn the new research area of 'environmental e-health'.

Dr. Scott is a lead co-investigator on a national Canadian study designed to identify and define suitable outcome indicators for demonstrating the value of e-health, and to achieve consensus on a minimum set of suitable outcome indicators. He was a co-investigator for the AHFMR State of the Science study examining socio-economic indicators and policy implications in relation to the impact of e-health. As an independent evaluator, Dr. Scott has brought his research expertise to the design and completion of evaluations of e-health applications in home telehealth, web-based tele-triage, tele-cardiology, and extension of hospital care to the home. Dr. Scott is a Founding member of the Canadian Society of Telehealth (CST) and the current Vice-President and President-Elect.

# Sharlene Stayberg - Telehealth Director Alberta Health and Wellness

Ms. Stayberg is presently the Telehealth Director for the Health Professions and Telehealth Branch of Alberta Health and Wellness. All provincial health authorities / boards access central support services for telehealth through this government office.

In her previous position as Administrative Director of the Telemental Health Service of the Alberta Mental Health Board, Ms Stayberg had the opportunity to lead development of a telehealth project, from a six-site pilot to an operational service offering clinical, education and administrative services to more than fifty sites. Ms. Stayberg has received the degree of Master of Public Health and a Credential in Health Services Administration from the University of Minnesota.

# **Appendix 3: NTOIP Workshop Syllabus**



# A Canadian Consensus Approach to Identification and Definition of Outcome Indicators for Evaluation of Telehealth



# National Telehealth Outcome Indicator Project (NTOIP) Workshop

**CALGARY**; 23 – 26 June 2003

#### Goal:

 To identify and clearly define tools (outcome indicators) that can be used by the broader telehealth community when comparing or performing evaluations of telehealth applications.

# Objectives:

- To review a summary report of the telehealth outcomes literature NTOIP Information Document.
- To identify candidate telehealth outcome indicators in four areas Quality, Access, Acceptability, and Cost.
- To identify which model is best for economic evaluation of telehealth applications.
- To confirm and initiate the telehealth outcome indicator definition process.
- To identify how identified and defined outcome indicators must be presented and disseminated to ensure acceptance and adoption by the broader telehealth community.
- To commit to support of the iterative consensus process.
- To commit to preparation and dissemination of the final consensus report and publications.

# Format:

Formal presentations or panels will be used to provide information and stimulate discussion. Breakout sessions will be used to encourage greater individual input, and reporting sessions will be used to ensure the group as a whole remains informed. Rapporteurs will capture and collate the thoughts and opinions proffered. The final report from the NTOIP Outcome Workshop will be a synthesis of the experience and expertise shared by you - the participants - in examining the various outcomes related topics, and will provide an informative document that will contribute to moving e-health forward in Canada and abroad.

# **Final Program**

Date	Time	Activity
Monday June 23	1100 - 1500	Arrival: Calgary Airport to Motel Village; own transportation
		Conference Hotel: Quality Inn Motel Village, 2359 Banff Trail NW
		Calgary, Alberta T2M 4L2. Tel: 403-289-1973. Fax: 403-282-1241
		Toll Free: 1-800-661-4667
	1900 - 2200	Evening Event:
		Optional.
		Informal supper by mutual arrangement of individual participants.
		Restaurant recommendations and price range available in registration
		package.
		Own transportation.

Date	Time	A	ctivity			
Tuesday	0750	Bus pick-up: Motel Village (Quality Inn) to Health Sciences Centre				
June 24	0800 - 0840	Registration: Mall, Health Sciences	s Centre			
		Refreshment: Mall, Continental Br	eakfast, Coffee, Tea, Bottled Water			
	0845 – 0900	Opening: Room 741, Health Scier				
		Welcoming Comments: Penny Jenn				
		Housekeeping Announcements: Bo				
		Introductory Comments: Richard Sc				
	0900 - 0925	NTOIP Description: Room 741, He	ealth Sciences Centre			
		Why are we here?				
		Speaker	Topic			
		Richard Scott	Project rationale and overview; key definitions; TOD model			
	0930 - 1030	Plenary I: Room 741, Health Sciences Centre				
			tors / measures are most suitable for applications for Quality and Access?			
		Speaker	Topic			
		Sandra Chatterton	CHIPP - indicators of quality and			
			access			
		Penny Jennett	Socio-economic indicators of quality and access			
	1030 - 1055	Refreshment: Mall - Coffee, Tea, Bottled Water				
1	1100 - 1155	Breakout I:  Which specific outcome indicators / measures are most suitable for broad evaluation of telehealth applications for Quality and Access?				
		Group 1 – Room 741	Group 3 – Room 743			
		Group 2 – Room 742				
	1200 - 1240	Reporting: Room 741, Health Scien Reconvene: Group summary reports minutes for Q&A	ences Centre s – each 10 minute maximum plus 10			
	1245 - 1400	Bag Lunch: Mall, Health Sciences Walking tour - optional: Health Te				

1400 – 1500	-	nces Centre tors / measures are most suitable for applications for Acceptability and			
	Speaker	Topic			
	Nancy Lefebre	Is measuring 'acceptability' of value, and if so how do we <i>really</i> measure it?			
	Sharlene Stayberg	'Costing' the e-health process – a practical model			
1500 - 1525	Refreshment: Mall - Coffee, Tea, Bottled Water				
1530 - 1625	Breakout II: Which specific outcome indicators / measures are most suitable for broad evaluation of telehealth applications for Acceptability and Cost?				
	Group 1 – Room 741	Group 3 – Room 743			
	Group 2 – Room 742				
1630 - 1710	Reporting: Room 741, Health Sciences Centre Reconvene: Group summary reports – each 10 minute maximum plus 10 minutes for Q&A				
1710 - 1730	Summary: Room 741, Health Sciences Centre Summary statement of Day 1 accomplishments: Richard Scott Housekeeping Announcements: Bonnie Rush				
1740	Bus departs from North entrance Health Sciences Centre for Motel Village				
1830 - 2030	Evening Event:  Modi restaurant; walking distance of hotel.  Group photo at 1845. Meal - 1900.				

Date	Time	Act	tivity			
Wednesday	0750	Bus pick-up: Motel Village (Quality Inn) to Health Sciences Centre				
June 25	0800 - 0900	Registration: Mall, Health Sciences	Centre			
		Refreshment: Mall, Continental Breal	kfast; Coffee, Tea, Bottled Water			
	0900 - 0915	Opening: Room 741, Health Science				
		Introductory Comments: Richard Scot				
		Housekeeping Announcements: Bonn				
	0915- 0945	Plenary III: Room 741, Health Sciences Centre				
		What model is best for economic analysis of telehealth				
		applications?				
		Speaker	Topic			
		Arto Ohinmaa	Is Cost-Benefit, Cost Effectiveness,			
			or Cost Utility analysis the 'way to			
			go'?			
	0945 - 1010	Refreshment: Mall - Coffee, Tea, Bottled Water				
	1015 - 1155	Breakout III:				
		What model is best for economic analysis of e-health applications?				
		Group 1 – Room 741	Group 3 – Room 743			
		Group 2 – Room 742				

1200 - 1240   Reporting: Room 741, Health Sciences Centre Reconvene: Group summary reports – each 10 minute maximum plus 10 minutes for Q&A   Lunch: Atrium - Health Sciences Centre								
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Housekeeping Announcements: Bonnie Rush								
Bus departs from North entrance Health Sciences Centre for Motel Village		1740	Bus departs from North entrance Hea	Ith Sciences Centre for Motel Village				
1900 - 2200 <b>Evening Event:</b>		1900 - 2200	Evening Event:					
Optional.			Optional.					
Informal supper by mutual arrangement of individual participants.			Informal supper by mutual arrangeme	ent of individual participants.				
Restaurant recommendations and price range available in registration			Restaurant recommendations and price	ce range available in registration				
package.			package.	-				
	1	1	Own transportation.					

Date	Time	Activity
Thursday		Departure:
June 26		Motel Village to Calgary Airport; own transportation
		OR
		Registration and attendance for the TRSI 2003

# **Appendix 4: Guidelines to Breakout Groups**

## Breakout Session 1 - Guidelines

Question: Which specific outcome indicators / measures are most suitable for broad evaluation of telehealth applications for quality and access?

#### Reference Material:

- 1. NTOIP Information Document (pp 21-22 for definitions; pp 36-45 for quality and access; pp 62-68 for the TOD Framework; pp 72-96 for appendices).
- 2. Presentation information Sandra Chatterton and Penny Jennett
- 3. Personal experience

#### Discussion Guidelines:

- a) Brief comment on TOD (take 5 minutes). Is TOD useful and acceptable as a working framework?
- b) Brief comment on the key definitions (take 5 minutes). Are the definitions useful and acceptable as working definitions?
- c) For the remaining 45 minutes, answer the following:
  - a. Within TOD, identify what outcome indicators might be useful for broad evaluation of e-health (i.e. not specific to a clinical activity) in the themes of quality and access; e.g.
    - i. Quality: Waiting Time; Quality of Life; Live Status
    - ii. Access: Utilization of healthcare services
    - iii. Select your top 5 indicators for quality and access
- d) Suggest possible measure for each of the top indicators
- e) Suggest possible tools for each of the suggested measures

## Reporter Guidelines:

- 1. TOD Framework: Summary of comments. Identify responses to questions.
- 2. Key Definitions: Summary of comments. Identify responses to questions.
- 3. Quality: List all identified outcome indicators underline top 5.
- 4. Access: List all identified outcome indicators underline top 5.
- 5. Measures: List possible measures for each indicator.
- 6. Tools: List possible tools for each measure.
- 7. 'Parking Lot' Issues: Identify other issues / topics that arose during the discussion that should be reviewed and debated at some later date.

## **Breakout Session 2 - Guidelines**

Question: Which specific outcome indicators / measures are most suitable for broad evaluation of telehealth applications for acceptability and cost?

Reference Material:

- 1. NTOIP Information Document (pp 21-22 for definitions; pp 45-60 for acceptability and cost; pp 62-68 for the TOD Framework; pp 72-96 for appendices).
- 2. Presentation information Nancy Lefebre and Sharlene Stayberg

## 3. Personal experience

#### Discussion Guidelines:

- a) (For the next 55 minutes). Within TOD, identify what outcome indicators might be useful for broad evaluation of e-health (i.e. not specific to a clinical activity) in the themes of acceptability and cost; e.g.
  - a. Acceptability: Client Satisfaction; Rate of Use
  - b. Cost: Travel Avoided: Staff
- b) Select your top 5 indicators for acceptability and cost
- c) Suggest possible measure for each of the top indicators
- d) Suggest possible tools for each of the suggested measures

# Reporter Guidelines:

- 1. Acceptability: List all identified outcome indicators underline top 5.
- 2. Cost: List all identified outcome indicators underline top 5.
- 3. Measures: List possible measures for each indicator.
- 4. Tools: List possible tools for each measure.
- 5. 'Parking Lot' Issues: Identify other issues / topics that arose during the discussion that should be reviewed and debated at some later date.

## **Breakout Session 3 – Guidelines**

Question: What model is best for economic analysis of e-health applications?

## Reference Material:

- 1. NTOIP Information Document (pp 51-52 for economic models and definitions).
- 2. Presentation information Arto Ohinmaa
- 3. Personal experience

## Discussion Guidelines:

- a) Can we recommend a single perspective from which to perform economic analyses of e-health; e.g. societal perspective (take 10 minutes)?
- b) Identify what economic model might be most useful for broad evaluation of e-health applications (take 45 minutes).
  - a. If no single model can be recommended, justify why not, and suggest what model might be used for what settings when evaluating e-health applications

#### Reporter Guidelines:

- 1. Perspective: Summarize which perspective is recommended and why.
- 2. Economic model: Summarize which model and why / why not recommended.
- 3. 'Parking Lot' Issues: Identify other issues / topics that arose during the discussion that should be reviewed and debated at some later date.

# **Breakout Session 4 - Guidelines**

Question: How must identified and defined outcome indicators be disseminated and presented to ensure acceptance and adoption by the broader e-health community?

#### Reference Material:

- 1. NTOIP Information Document (pp 16-18 for achieving consensus; pp 62-68 for TOD Framework).
- 2. Presentation information Penny Jennett and Richard Scott.
- 3. Personal experience.

#### Discussion Guidelines:

- a) What is the best way to disseminate the identified and defined indicators (take 20 minutes)?
- b) How can acceptance and adoption be encouraged (take 35 minutes)?

# Reporter Guidelines:

- 1. Dissemination: Summarise recommendations for means of dissemination.
- 2. Acceptance and Adoption: Summarise recommendations for encouraging acceptance, and recommendations for encouraging adoption.
- 3. 'Parking Lot' Issues: Identify other issues / topics that arose during the discussion that should be reviewed and debated at some later date.

# **Appendix 5: Worksheet Used to Develop the Minimum Influential Dataset**

# Minimum Influential Dataset Activity

## **INSTRUCTIONS**

- 1. Place yourself in the position of ONE of the groups it is intended to influence (e.g. general public, policy maker, etc).
- 2. Consider ONE parameter (e.g. Need, Equity, etc.) and decide if that parameter might significantly influence your decision to support telehealth. If no leave the square blank; if yes, place a check mark in that box.
- 3. Identify succinctly (key words only) what specific issue / aspect around that parameter would influence your decision to support telehealth. Write this on a PINK piece of paper (LARGE print).
- 4. IF you know (directly or indirectly) of a situation where information about this parameter has actually influenced that specific group, write this on a BLUE piece of paper (LARGE print) plus your name (if explanation needed).
- 5. Repeat steps 2 to 4 for the next parameter.
- 6. Repeat steps 1 to 4 for the next group.

## REASSEMBLE

We will gather at 1:30 in Room 741 to collate our views and experience.

Health Values	General Public	Policy Maker (Planner)	Decision Maker (Politician / Manager)	Funder	Service Provider	Media	
Need							
Equity							
Cost							
Quality							
Access							
Impact							
Outcome(s)							