



# ***Telehealth and e-Health Policy Considerations for Alberta***

**A report prepared by the Health Telematics Unit,  
University of Calgary for Alberta Health and Wellness**

**Global e-Health Research and Training Program  
Health Telematics Unit  
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# 1. Main Messages

## ***Where we are:***

- Alberta's commitment to the application of e-health solutions is evident through its funding and leadership.
- Alberta enjoys one of the most advanced groups of e-health (telehealth and health informatics) initiatives in Canada.

## ***What the literature (grey and formal) says:***

- There is very little overt (published and accessible) evidence of e-health policy in Alberta.
- There is some evidence of limited e-health policy development in Alberta.
- On an e-health policy maturity scale of 1 (highest) to 4 (lowest), Alberta lies at an early Stage 2.
- No defined strategy for broad (transparent and public) e-health policy debate in Alberta could be located.
- No defined and overt (published and accessible) strategy for e-health policy formulation in Alberta could be located.
- 53 telehealth or e-health related policy issues can be identified from the grey and formal literature.

## ***Lessons Learnt:***

- From the 53 telehealth or e-health related policy issues identified, 34 *relevant* to Alberta can be identified.
- Of these, 16 *priority* e-health related policy issues have been identified for Alberta Health and Wellness under three themes: 'Operational', 'Data Stewardship', and 'Inter-jurisdictional'.
- It is often difficult to consider any of the e-health policy issues in isolation, since many single issues are confounded by aspects of others.
- The 'inter-jurisdictional' nature of many of the issues is pervasive requiring that common solutions across jurisdictions be sought, rather than each jurisdiction considering and responding to an issue independently.
- The priority e-health related policy issues impact both Alberta and its inevitable link with other Federal, Provincial, Territorial, and global activities.
- A clear definition of 'data stewardship' was absent, and has now been described.

## ***Moving forward:***

- The 3 priority e-health policy themes and 16 e-health policy issues provide focus for Alberta Health and Wellness.
- Potential policy options, directions, and consequences associated with each of these issues can now be examined, and used to inform and influence the e-health policy process in Alberta and elsewhere.

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## 2. Executive Summary

This study was commissioned to better inform Alberta Health and Wellness (AHW) of the spectrum of e-health policy issues, and of these which are of most relevance to Alberta, in particular AHW. e-Health is considered an umbrella term, and to be comprised of 'health informatics' and 'telehealth'.

Based upon focussed literature searches and reviews, the report identifies 53 e-health related policy issues. These were first differentiated into those of most relevance and impact to Alberta, and then into those of most relevance and impact to Alberta Health and Wellness. Thirty-five e-health policy issues of relevance to Alberta were identified under 8 themes. Subsequently 16 issues of priority to Alberta Health and Wellness were differentiated, under three themes of 'Operational', 'Data Stewardship', and Inter-jurisdictional, as follows:

**Data Stewardship** - Privacy protection, Documentation, Data security, and Information quality.

**Operational** - Risk management, Liability, Referral patterns, Ownership, Human resources, Reimbursement, Evaluation, Business case, and Funding.

**Inter-jurisdictional** - Inter-jurisdictional billing, Locus of consultation, and Integration.

Overall, it is considered the issues identified under Data Stewardship would have highest priority. But every effort must be made to concomitantly address the issues identified under the themes of Operational and Inter-Jurisdictional. This will place AHW in a very informed and strong leadership position, and result in greater integration of e-health. Addressing of these issues must be achieved through clear and implemented strategies with centralised facilitation.

A limitation of the report is that the issues identified were developed from the literature, and are not exclusive. Other issues within these themes may be identified with time or by other routes, and if appropriate should be incorporated into the current listings. In addition, rationalising, categorising, and selecting of the original 53 e-health related policy issues to

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provide 16 of most relevance to AHW was a subjective process and based upon expert opinion; the opinion of others may differ.

When implementing and integrating e-health, it is clear from the focused literature searches and reviews that technological barriers are no longer a major issue. Rather, policy related issues remain major impediments to the further development of e-health and realization of its full potential.

Because e-health directly impacts issues of paramount concern to the public and across federal / provincial / territorial healthcare systems, its policy needs and directions require thoughtful, open debate by all interested parties. By providing a limited number of policy themes and issues to pursue in the immediate future, this report provides focus for AHW. Moving forward to identify potential consequences of policy options and directions related to these policy issues will inform and influence the e-health policy process in Alberta and elsewhere.

## 3. Introduction

### 3.4 Background

The advent of telehealth <sup>1</sup> has seen the rapid growth and application of information and communications technology (ICT) in many areas of healthcare (Jennett et al., 2003a, 2003b). Also, the recent evolution of e-health<sup>2,3</sup> to embrace telehealth has effectively created a 'borderless world'. This is a characteristic that does not fit easily into traditional domestic (national, provincial, territorial) or regional health systems largely unfamiliar with unfettered inter-jurisdictional services. In our networked world there is an unprecedented and growing interdependence between jurisdictions, and there is significant benefit to be gained from the networked flow of health information and knowledge amongst and between jurisdictions. However, inappropriate policy in any single jurisdiction may hamper or even cripple the ability of e-health to fulfill its potential [Scott et al., 2002].

Even within our own borders the spectrum and complexity of issues surrounding e-health is not fully understood. Policy, at least in theory, determines the rate and direction of development for healthcare initiatives. In the case of e-health, transparent policy debate and formulation is lagging behind technology development and application (Bilimoria, 2003; Simpson, 2002; Rigby, 1999). Indeed, Simpson notes that "*As health care facilities adopt telemedicine, policies - both legal and internal - will be a key issue. Enablers or impediments? That depends on whether policies can keep up with technology.*" Any policy decisions made around the myriad issues identified in this report will significantly impact the future availability, acceptability, effectiveness, and cost of e-health services in Alberta, and influence what happens elsewhere.

Organisations and governments may well have developed some e-health policy, but to the general e-health user, the reality appears different. For example, a recent global Medline search combining e-health / telehealth / telemedicine linked with policy / guidelines / regulations / law identified only 187 citations, many of which were not relevant (offering no discussion and debate of specific issues). Similarly, a very recent search of the Government of Alberta website (<http://www.gov.ab.ca/home/>) for 'telehealth policy' revealed 10,430 'hits' for policy, 165 for telehealth, and only 1 for 'telehealth policy'. Other web-based approaches have found little in terms of specific e-health guidelines (e.g. Jacobson and Selvin, 2000). Overall, remarkably few e-health policy related documents or

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<sup>1</sup> Telehealth is the application of information and communications technology (ICT) to "deliver health services, expertise and information over distance, geographic, time, social and cultural barriers." (Reid, 1996).

<sup>2</sup> The term 'e-health' is gaining use as an umbrella term for the use of any form of ICT to improve or enable health and health care; it bridges both the clinical and non-clinical sectors and includes both individual and population health-oriented tools (Eng, 2001). e-Health can be considered to be composed of two elements – health informatics (related to collection, analysis, and movement of data to support health information and healthcare) and telehealth (related to delivery of health information and healthcare, and direct or indirect contact with a recipient) (Wang et al, 2003).

<sup>3</sup> It is increasingly difficult to separate policy issues associated with telehealth from those associated with e-health overall. For this reason the term e-health has been adopted for use throughout this report.

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publications exist (Loane and Wootton, 2002), and those that do warn of the urgent need to address the issue (Bilimoria, 2003; Simpson, 2002; Loane and Wootton, 2002; Rigby, 1999).

### 3.5 Study purpose and design

This study was commissioned to better inform Alberta Health and Wellness of the spectrum of e-health policy issues, and of these which are of most relevance to Alberta, in particular Alberta Health and Wellness (AHW). The report identifies e-health policy issues and differentiates those of most relevance and impact to AHW from those of most relevance and impact to other jurisdictions (e.g. professional groups, health regions, federal government).

In completing this commission, the Health Telematics Unit (HTU) team:

- Worked closely with the Director, Provincial Telehealth Program;
- attended and summarised the content from two national, policy related conferences;
- designed and performed two focused and structured literature searches;
- collated and summarised the findings from these literature searches and conferences;
- synthesised and assessed the available information, applying draft e-health policy tools;
- prepared this final report <sup>4</sup>.

In addition, and to fulfill its final responsibility, the HTU team anticipates being requested to disseminate the results through being asked to present the findings to the Provincial Telehealth Committee (PTC) or other audience in Edmonton (date and venue to be chosen in cooperation with the Director, Provincial Telehealth Program).

### 3.6 What is e-health policy?

A recent definition of 'e-health policy' ("*a set of statements, directives, regulations, laws, and judicial interpretations that direct and manage the life cycle of e-health*") [Scott et al., 2002]) has been adopted for this report.

Using this definition, four categories of policy maturity for any jurisdiction have been described (Scott, 2003). These are, beginning with the strongest:

- **Stage 1** – Regulations and laws *governing* e-health activity. This represents well-established development of policy, with it being formally embedded into the administration of the jurisdiction.

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<sup>4</sup> This policy synthesis draws together published literature, 'grey' literature, 'decision makers' experience; and researchers' knowledge and experience in order to make best practice recommendations regarding priority e-health policy issues for the province of Alberta. In concert with recognised practice for policy syntheses, it is presented in the 1:3:25 format recommended by Health Canada, as follows: a single page of bullet points documenting the main messages; an executive summary of no more than three-pages; and a full report of no more than twenty-five pages plus appropriate appendices.



- **Stage 2** – Statements, directives, guidelines defining and delimiting e-health activity. This shows clear evidence of formal written material that governs at least some e-health activity.
- **Stage 3** – Evidence of pro-active consideration of e-health activity. This is an important stage, and might be where a jurisdiction establishes mechanisms and / or funding programs to move e-health initiatives forward.
- **Stage 4** – Broad suggestions of intended direction encompassing e-health activity. This is the weakest, yet probably most common ‘policy statement’ for any jurisdiction.

Based upon the work undertaken to prepare this report it is evident that Alberta has some e-health related policy (for example; standards development work, telehealth operation manual, privacy legislation, draft consent documents). For this reason, and using this e-health policy maturity scale, Alberta would be considered to currently lie at an early Stage 2.

### 3.4 Who makes e-health policy?

Policy is not the sole purview of politicians. According to Eng (2001) both public and private sectors make e-health related policy. For the public sector this policy is developed primarily through legislation and regulatory initiatives, whilst for the private sector it is primarily through purchasing, investments, and implementation decisions. Each approach determines the context in which e-health applications are developed and deployed. In this process, public policy-makers balance the uncertainties associated with voluntary industry standards and self-regulation with more direct legislative and regulatory options. Thus, government agencies have a major role in e-health policy development given their mandate to promulgate regulations governing related areas, such as data security, consumer protection and fraud, and approval and sale of prescription drugs and medical devices. Such policy has broad ranging societal impact. In contrast, the private sector (e.g., health care executives, e-health practitioners as professionals, and large employers) essentially set e-health policy within their own sphere of influence (e.g. organization or representative body) (Eng, 2001). These private sector policies do impact public policy.

Based on this perspective, Figure 1 (below) shows a simplified diagram of a general hierarchical e-health policy cascade and feedback process across policy ‘levels’ for Alberta. Note that the public is included both as the backdrop to the process, and as an active participant.

As noted on the Office for Health and the Information Highway (OHIH) website, “currently, the protection of personal health information in Canada is shared among federal, provincial, and territorial governments with a “patchwork” of legislation, policies, regulations, and voluntary codes of practice”. No more can be said of whatever policy exists for other e-health related issues.

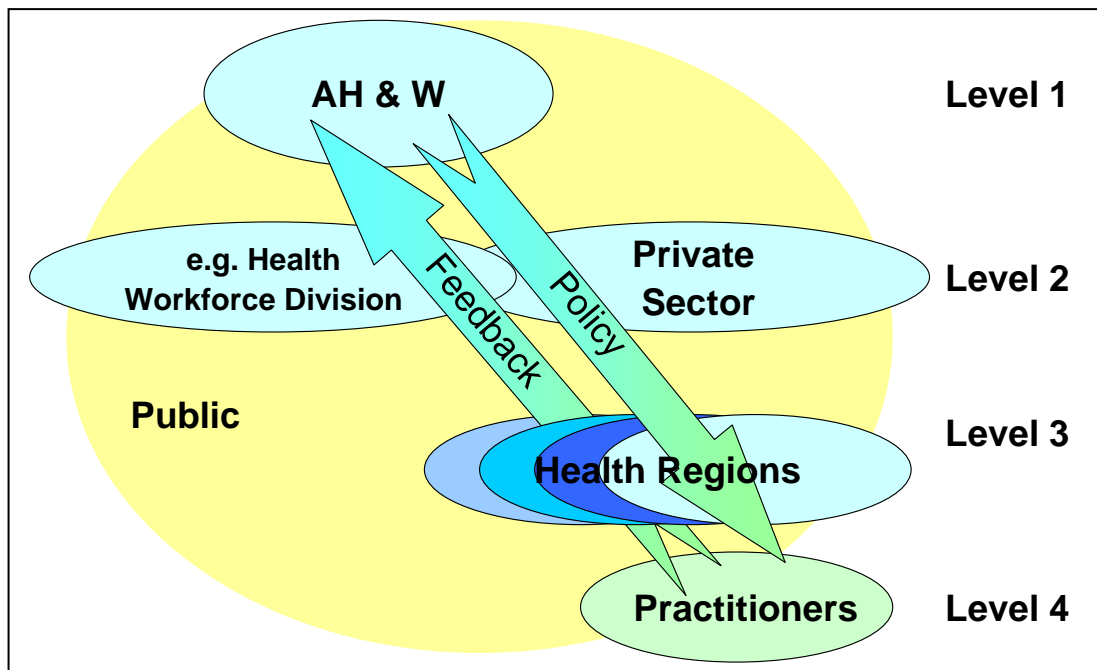


Figure 1. Simplified diagram of a general hierarchical e-health policy cascade and feedback process across policy 'levels' for Alberta (after Scott RE, 2003).

Despite the differences between public and private sector policy and their respective impact, efficient inter-jurisdictional<sup>5</sup> functionality of e-health requires both. Further such functionality requires that any e-health policy decisions are evidence-based ('right' for the time), complementary (facilitate 'inter-jurisdictional' activity), and have benefited from thoughtful input from all levels and sectors (transparent).

<sup>5</sup> *Inter-jurisdictional* is used to refer to activity that takes place between two or more jurisdictions. The term 'cross-jurisdictional' is discouraged since it implies bi-directional interaction and crossing of a single barrier. e-Health has the potential to cross many (and different types of) barriers in a single activity, which is better implied through use of the term *inter-jurisdictional*. (Scott et al., in press).

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## 4. What are the e-health policy issues?

In order to inform the goal of the study, focussed literature searches and reviews were performed to identify the spectrum of policy issues that have been described.

### 4.1 Focussed literature searches and reviews

Three focussed literature searches and/or reviews were performed. The first search was a PubMed and Internet-based search (refer to Appendix 1 for search strategies used). The second search used the Telemedicine Information Exchange (TIE) database exclusively (refer to Appendix 1 for search strategies used). The third was a review of material from the two national policy related conferences that were attended (refer to Appendix 2 for a summary of the National Telehealth Outcome Indicators Project (NTOIP) workshop, and Appendix 3 for a summary of the Telehealth Research Summer Institute (TRSI) conference).

Overall, the results of the searches yielded relatively few applicable publications, articles, or reports. Many other 'snippets' of e-health policy relevant information or perspectives are located in documents of professional groups, which are often difficult to identify through normal literature and Internet-based search techniques (e.g. College of Physicians and Surgeons (CPSA) statement on Practice of Medicine by Telecommunication across Provincial Boundaries in the CPSA Newsletter 'The Messenger').

Information from each search was reviewed, and a comprehensive listing of e-health policy issues was generated (Section 4.2). This also offered an unplanned opportunity to identify actors involved in e-health policy development, which has been added into this report (Section 4.5).

### 4.2 e-Health policy issues identified

A total of 53 e-health policy related issues<sup>6</sup> were identified from the searches and reviews of the e-health literature. These are listed alphabetically in Table I below.

The issues identified each have relevance to Alberta. These issues include confidentiality and the patient's rights of access (Stanberry, 1997; Pyper et al., 2002), data protection and security (Stanberry, 1998a; Buckovich et al., 1999), access and authorisation (Scott et al., in press), malpractice (Stanberry, 1998b), intellectual property (Beauregard and Beauregard, 2000), product liability and jurisdictional issues (Stanberry, 1998c), risk management (Wallace et al., 1999), licensing (Nohr, 2000; Jacobson and Selvin, 2000; Pong and Hogenbirk, 1999), reimbursement (Pong and Hogenbirk, 2000), and others

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<sup>6</sup> The term 'issues' is used loosely. When extracting these from the literature a lack of clear definition or description sometimes made it difficult to discern precisely the aspect of concern, thus there may be some overlap or redundancy in the list of issues identified.

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(Hasham, in press; Jennett et al., 2003c). More recently, a 'Glocal' e-Health Policy Matrix Model has been described that encompasses eight policy *levels*, nine policy *themes*, and eight policy *actor* categories (Scott, 2003). In addition, discussion with Albertan decision- and policy-makers indicates that reimbursement, privacy, confidentiality, data stewardship, and consent are amongst the most urgent issues. Also, the national Advisory Committee on Health Infostructure views privacy, security, cost, reimbursement, licensure and the availability of consistent, high-quality, clinically relevant data as key issues (ACHI, 2001). Some issues (e.g. consent) are considered to require urgent resolution, whilst others (such as internal trade between Ministries, physician licensing issues, reciprocal billing requests / province to province billing), have received relatively little attention. Alberta has addressed the issue of consent in recent draft documents.

One of the most pertinent and comprehensive publications identified was the recent National Initiative for Telehealth (NIFTE) Framework of Guidelines (NIFTE, 2003). This is a structured set of statements designed to assist individuals and organizations in the development of policy, procedures, guidelines and/or standards. Although the NIFTE document does not identify and address the broad number of policy issues identified in this report, it is a sound, consensus based document of value and relevance to Alberta, Canada, and elsewhere.

Additional issues were also identified through the NTOIP workshop (Appendix 2) and TRSI conference (Appendix 3). The need for a stronger evidence-base for e-health was identified, emphasising the need for rigorous research using a standardised approach to application of outcome indicators. The TRSI reaffirmed the importance of knowledge translation and knowledge transfer, and the need for a global and societal perspective to be recognised when evaluating e-health solutions. The need for common definitions and standards for outcome indicators was highlighted, and the need to follow the life cycle (implementation, integration, monitoring) of any e-health application was recognised. Strategies identified as potentially beneficial to e-health policy debate and formulation included: educating; social marketing; creating a demand or expectations; developing a knowledge warehousing strategy; and formulating a broad and collaborative strategy for e-health policy debate amongst all stakeholders (decision- and policy-makers, the public, healthcare practitioners, and researchers).

A number of e-health policy related issues were also identified during the 2002 Telehealth Research Summer Institute (TRSI, 2002), and recommendations for their resolution proffered. The need for sound policies related to the human resource implications resulting from e-health initiatives was identified (e.g. changes in professional roles, organizational change management, and stakeholder readiness for change). It was emphasized that sustainability of telehealth depends on its solid and seamless integration into existing services rather than initiatives being seen as "adjuncts." A number of policy considerations were seen to arise from this that will require attention from funding bodies, researchers, policy makers, and professional organizations, including: the slow pace of resolution for

policy implications related to remuneration and licensure; the need for integration to remain a core tenant despite its continued challenges to policy development; the need for policy to clearly support integration of e-health with traditional services, as well as newer initiatives such as the Electronic Health Record (EHR); and the need for policy development to be attentive and responsive to its impact from local through to global levels. In addition, while participants generally recognized there are benefits to developing consensus on standards for evaluation tools and methods, implementation challenges remain - leaders in research and evaluation need to take a greater role in the translation and dissemination of results to support a consensus building approach.

<b>Table I. e-Health Policy Related Issues Identified from the Literature and Categorization using the 'Glocal' e-Health Policy Matrix Model (Alphabetical Listing)</b>					
Issue	Matrix*	Issue	Matrix*	Issue	Matrix*
Access	Op	Evaluation	Op	Privacy protection	Et
Accountability	Le	Focal point of consultation	Le	Privileging	Pr
Accreditation	Ins	Funding (at all levels)	Op	Professional-patient relationships	Pr
Building ICT infrastructure	Col	Government support	Op	Readiness	Ins
Business case	Op	Human Resources	Op	Reciprocal billing	Op
Certification	Pr	Information quality	Op	Referral patterns	Pr
Change Management	Ins	Integration	Op	Registration	Pr
Competence	Ins	Inter-jurisdictional billing	Op	Regulatory support and clarification	Com
Confidentiality	Et	Inter-Ministry trade	Op	Reimbursement	Pr
Consent	Et	Interoperability	Int	Responsibilities	Ins
Control	Op	Inter-professional relationships	Pr	Risk management	Le
Credentialing	Ins	Liability	Le	Roles	Pr
Data Stewardship (records)	Op	Licensure	Pr	Scope of practice	Op
Data Security (encryption)	Op	Malpractice	Le	Standards	Int
Development of networks	Op	Organization of medical services	Op	Sustainability	Op
Documentation	Op	Ownership	Op	Technological reliability	Int
Due diligence	Op	Phased Infrastructure	Op	Training	Ins
Ethics	Et	Planning and coordination	Op		
* Glocal e-Health Policy Matrix Model categories: Pr = Professional; Op = Operational; Ins = Institutional; Et = Ethical; Le = Legal; Cu = Cultural; Col = Commercial; Com = Communication; Int = Interoperability.					

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A common approach to addressing all of these issues is predicated upon a common understanding of their meaning. Thus it is desirable to have each identified issue clearly defined to ensure consistent understanding of the issue. Often this was not done in the literature, rather it was often assumed that we inherently ‘know’ the meaning of a term used. This is a dangerous assumption to make.

### 4.3 e-Health unique policy issues

A principle espoused in the NIFTE guidelines, and gaining wide acceptance, is that e-health specific policy should only be developed if and when current health policy does not address the issue, or revision of current health policy cannot accommodate the issue. This pragmatic approach supports the goal of seamless integration of e-health into the traditional healthcare system. It also assumes that some e-health unique policy issues exist, which still remains a topic of debate. The Institute of Medicine addressed this issue in 1996 (IOM, 1996):

“For telemedicine [telehealth] practitioners, electronic transmission of patient health information in various formats is part of their every day job. For example, store-and-forward applications are quite common. This means that a telemedicine practitioner at a remote rural site can examine a patient and send a video clip or a photographic scan of the patient, along with the patient's medical record, by e-mail via the Internet or dedicated line to a distant consulting practitioner. In a live interactive videoconference session, a patient may sit in the same room as a health presenter, video camera man and technician. The consulting practitioner, who appears on the video monitor, may also have non-medical staff in his or her room. What should be done with the videotape of the consultation? How should Internet transmissions of identifiable information be handled? What types of privacy contracts should be made between the non-health staff and the practitioner? Can e-mail information be de-identified when part of the file includes scanned photos or video? Many of these types of privacy questions are unique to the practice of telemedicine.”

### 4.4 Categorizing the e-health policy issues identified

To better structure the list of e-health policy issues, the thematic aspect of the ‘Glocal’ e-Health Policy Matrix Model (Scott, 2003) was used to simplify and categorise the listing into policy themes, as identified in Table I (above). This model, largely based upon experience within the Global e-Health Research and Training Program of the Health Telematics Unit, has identified eight policy *levels* (e.g. Individual, Community, Program, Organisation, etc), eight policy *actor* categories (e.g. International bodies, NGO's, Governments, Agencies, etc.), and nine policy *themes* (e.g. Professional, Operational, Ethical, Legal, etc.).

*It should be noted that the Glocal e-Health Policy Matrix Model is simply a tool to assist in structuring debate, and that placement of any issue within a particular ‘policy theme’ (or ‘policy level’ or ‘actor category’) does **not** imply exclusivity over the existence, impact,*

examination, or resolution of that issue. The inter-jurisdictional nature of e-health demands broad input into the debate and answers to all policy issues.

#### 4.5 e-Health policy actors identified

Based upon the literature searches and review, the opportunity was taken to also identify actors involved in e-health policy development (Table II, below). Although not a comprehensive listing, it is anticipated it will prove a useful addition to the report by illustrating the spectrum of groups with a vested interest and role to play in e-health policy development. Additional information is provided in Appendix 4.

<b>Table II. Alphabetical Listing of Some Canadian e-Health Policy Actors Identified Through the Literature Searches</b>	
Advisory Committee on Information and Emerging Technologies (ACEIT)	College des medecines du Quebec (CMQ) *
Alberta Health and Wellness	College of Physicians and Surgeons of Alberta (CPSA)*
Alberta Health Regions and Boards	College of Physicians and Surgeons of New Brunswick (CPSNB) *
Alberta Medical Association	College of Physicians and Surgeons of Nova Scotia *
Alberta Wellnet	College of Physicians and Surgeons of Saskatchewan (CPSS) *
Canada Health Infoway Inc. (CHII)	Federal Government
Canadian Institute for Health Information (CIHI)	Federal Healthcare Partnership (FHP)
Canadian Medical Association	Federation of Medical Licensing Authorities of Canada (FMLAC).
Canadian Medical Protective Association (CMPA)	Health Care Coordination Initiative (HCCI) (see Federal Healthcare Partnership (FHP))
Canadian Nurses Association	National Initiative for Telehealth (NIFTE)
Canadian Society of Telehealth (CST)	Office of Health and the Information Highway (OHIH)
CANARIE	Ontario College of Physicians and Surgeons (OCPS)
COACH: Canada's Health Informatics Association	Western Health Information Collaborative (WHIC)
College of Family Physicians and Surgeons of Canada (CFPSC) *	
* Other than for those Colleges of Physicians and Surgeons noted above, it has been reported that no other Colleges have explicit policies, statements, guidelines or other regulation on 'telemedicine' (Hasham et al., in press).	



## 5. Perspective - Alberta Health and Wellness

A primary goal of this study is to identify which of the identified e-health policy issues are of most relevance to Alberta, and in particular to Alberta Health and Wellness. This pragmatic goal must not overshadow the identified need for Alberta's policy approach to be attentive and responsive to its impact from local through to global levels. e-Health in Alberta (or one Department) is not - must not be - isolated from what is happening locally, nationally, and internationally. Hence the use of the term 'Glocal' (*G*lobal + *L*ocal), originally introduced by Kickbusch (1999).

To understand which issues are of most relevance, three approaches were considered:

- a) Frequency of issues identified.  
Quantitatively, the literature would suggest priority issues are reimbursement, licensure, confidentiality / privacy, lack of clinical protocols, and a lack of solid evaluative research. This was considered too limiting to be of practical value since this report, which represents the first known attempt to broadly identify the spectrum of e-health policy issues, shows many other issues to be deserving of consideration.
- b) Use of e-health models.  
Only one recently developed model could be identified that might assist (Wang et al., 2003).
- c) Conceptualising the issues in relation to anticipated needs of current and planned e-health activities in Alberta.  
Aligning policy issues with those goals in mind was considered the most focused approach.

Option c), informed by option b), was adopted, using the literature as a guide. The process was performed in a structured manner, and was based upon conceptual models described below. None the less, the process of rationalising and categorising the original 53 e-health related policy issues, and of selecting the 16 of most relevance to AHW, was a subjective process and based upon expert opinion.

### 5.1 The e-health ICT impact model

In this model (Wang et al., 2003) the seemingly endless number of possible ways of describing the application of e-health has been reduced to two; the collection, analysis, and transfer of data and information (*health informatics*), and the specific application of this data and information in providing healthcare or healthcare related information (*telehealth*).



The e-Health ICT Impact Model (Figure 2) begins with data (health informatics), which is operated on by the ICT functions described in the 'onion skin' layers of the model, and results in an application (telehealth). As its conceptual base the model uses ICT, a term and concept with which people are familiar. Each component of ICT (Information, Communication, and Technology) is represented as a single layer of the onion-skin. The Information layer is composed of a cyclical interaction between data, analysis, and action; the Communications layer is focused on the issue of Interoperability; and the nucleus identifies the specific issues to be considered – here technology issues. Although the model was developed to address technology issues, the principle of the model can be applied more broadly.

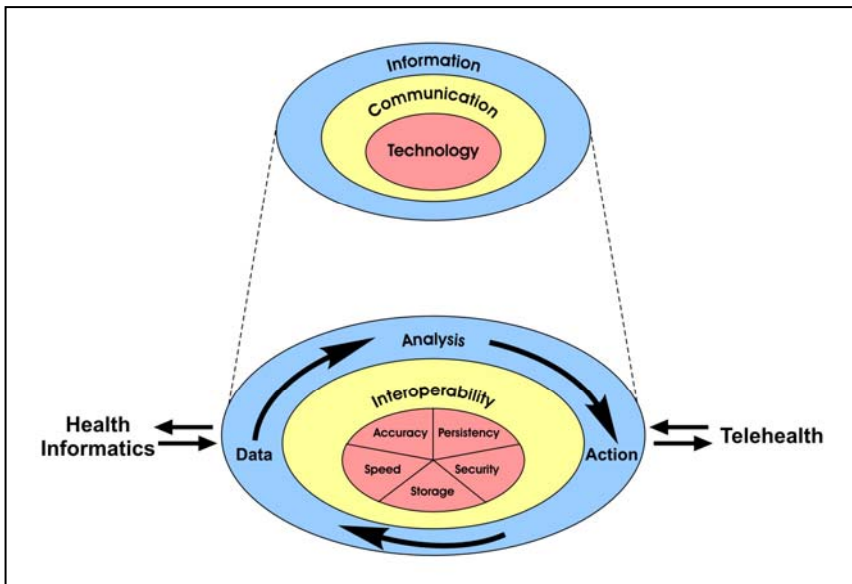


Figure 2. The e-Health ICT Impact Model (Wang et al., 2003).

## 5.2 Current and planned e-health activities in Alberta

Alberta is actively pursuing an agenda for health reform, informed in large part through the Mazankowski report (Mazankowski, 2001), other federal and provincial healthcare reform reports (Romanow, 2002; Kirby, 2002; Fyke, 2001; Clair, 2000; National Forum on Health, 1997), and the First Ministers' Health Accord (FMHA, 2003).

A review of the recommendations described in the Mazankowski report shows many areas in which e-health could have an impact. Of the 10 groups of recommendations for reform, 8 contain some element or specific recommendation related to e-health or having relevance to e-health policy. Examples would include: providing Albertans with better information about how to stay healthy; reducing waiting times by introducing centralized booking, and posting waiting times for selected procedures on a website; investing in technology and establishing an electronic health record; providing long term funding for technology and information technology systems; continuing to support research, evidence-based decision

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making, and Alberta's role as a leading centre of health and medical research. Several of these have already been acted upon.

Other Federal and provincial reports have each, to varying degrees, identified technology (including information and communications technologies such as telehealth) as a key tool to address the diverse and changing needs of healthcare in Canada. For example, the Romanow Report identified such technologies as being particularly important in addressing the needs of rural and remote communities.

Finally, the First Ministers' Health Accord recently re-affirmed the importance of accessibility to quality information to facilitate quality care, patient safety, sustainability, better utilization of resources, and protection of personal information (FMHA, 2003). Specific focus was given to patient safety, health human resources, technology assessment, and the sharing of best practices to make healthcare more efficient and improve its quality.

Alberta is concurrently pursuing several specific e-health initiatives, each of which inter-relate to one another. These are:

**a) *Telehealth.*** Initiated through Alberta Wellnet, the Provincial Telehealth Program now has a significant scope of practice. As of the end of 2003, a total of 227 sites were active, with 12 other Regional Health Authority sites planned (total of 239 sites). These included 140 Regional Health Authority sites, 11 Alberta Cancer Board sites, 14 Alberta Mental Health Board sites, 2 Alberta Health and Wellness sites, 25 radiography / ultrasound sites, 23 First Nations sites, and 12 other non-Health Authority sites. This growing network alone creates novel inter-jurisdictional policy issues that must be clearly identified, understood, and addressed.

**b) *Health Informatics.*** Several health informatics initiatives are being pursued:

- 1) ***Electronic Health Record (EHR).*** Alberta's EHR is a clinical health information network that links community physicians, pharmacists, hospitals, and other authorized health care professionals across the province. It lets these health care practitioners see and update health information (e.g. patient allergies, prescriptions, and laboratory tests).
- 2) ***Electronic Medical Record (EMR).*** An EMR is similar, but is a local electronic health information system installed at a medical clinic allowing secure, comprehensive computer patient records to be kept locally by a healthcare provider. Support for implementing the EMR is available through the Physician Office System Program (POSP).
- 3) ***Physicians Office Support Program (POSP).*** This program is jointly supported by the Alberta Medical Association (AMA) and Alberta Health and Wellness (AHW). Its goal is to encourage physicians to implement

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information technology in their practices by providing financial assistance and other resources.

- 4) **Pharmacy Information Network (PIN)**. This application stores drug and allergy information, provides confidential access to patient medication histories, and provides alerts and decision support tools when prescribing medications. PIN, one of three initiatives under the first release of the Provincial Electronic Health Record (announced by Alberta Health and Wellness on 21 October 2003), is targeted for province-wide deployment and to be used by 50% or more of physicians by April 2004. Province-wide deployment is being funded through a \$16-million investment by Canada Health Infoway (announced 7 November 2003).

Providing 'infostructure' support is another initiative through the **Alberta SuperNet**. This is an Alberta government infrastructure project designed to provide high-speed, high-capacity broadband network access linking 4,700 public facilities (e.g. government offices, healthcare facilities, libraries), and through service providers to businesses and residences, in 422 Alberta communities. Alberta SuperNet is a partnership involving the government and private enterprise.

### **5.3 What are the major e-health policy issues for Alberta?**

An adaptation of the e-Health ICT Impact Model, in conjunction with the perspective provided by considering current and planned e-health activities in Alberta, was used to further rationalize the policy issues identified from the literature and first categorised using the 'Glocal' e-Health Policy Matrix Model. Some issues were transferred from one theme to another, some were combined, and others were posted within a new theme (e.g. Inter-jurisdictional). The rationalization process is described in Appendix 5. During this process two perspectives repeatedly arose. First, it is often difficult to consider any of the issues in isolation, since many single issues are confounded by aspects of others. Second, the 'inter-jurisdictional' nature of many of the issues was pervasive – it will be desirable to seek common solutions across jurisdictions, rather than each jurisdiction consider and respond to an issue independently.

As a result, of the rationalization process, 34 specific e-health policy issues were identified that could be linked with the projected development of e-health (telehealth and health informatics) within the province of Alberta (Appendix 6).

### **5.4 What are the major e-health policy issues for AHW?**

The policy issues identified for Alberta were then considered from the frame of reference of Alberta Health and Wellness. For example, some policy issues could be considered of primary (not exclusive) concern to Health Regions, whilst others might be construed as being of primary concern at the Federal level. Again, a major confounding issue is that exclusivity over the consideration, debate, and resolution of any issue does not exist.

In determining which e-health policy issues are of most relevance to Alberta Health and Wellness, the following was considered. The Alberta government sets strategic direction for the provincial healthcare system through establishing policy, legislation, and standards. Policy should lead e-health development and facilitate e-health integration. The categorizing of e-health policy issues into themes provided some guidance, e.g. providing focus on issues that may be of primary impact in the ‘Operational’ sense, which was considered to equate to issues of relevance to AHW.

It was concluded that the e-health policy issues identified under the three themes ‘Operational’, ‘Data Stewardship’, and ‘Inter-jurisdictional’ are the most relevant for Alberta Health and Wellness to address at this time. These are listed in Table III below.

<b>Table III. e-Health Related Policy Themes and Issues of most Relevance to Alberta Health and Wellness</b>			
<b>Theme</b>	<b>Data Stewardship</b>	<b>Operational</b>	<b>Inter-jurisdictional</b>
<i>Issues</i>	<i>Privacy protection</i>	<i>Risk management</i>	<i>Inter-jurisdictional billing</i>
	<i>Documentation</i>	<i>Liability</i>	<i>Locus of consultation</i>
	<i>Data security</i>	<i>Referral patterns</i>	<i>Integration</i>
	<i>Information quality</i>	<i>Ownership</i>	
		<i>Human resources</i>	
		<i>Reimbursement</i>	
		<i>Evaluation</i>	
		<i>Business case</i>	
		<i>Funding</i>	

This listing of issues may well raise challenge. For example, many of the operational issues identified might be viewed as a responsibility of Regional Health Authorities (RHA’s) in their service delivery role. Others such as ‘human resources’ may be viewed as the role or responsibility of a specific government agency, here the Health Workforce Planning Unit. However, a review of the health and telehealth related roles, responsibilities, and mandates of different groups in Alberta suggests validity to the listing (Table IV). The Minister of Health and Wellness, aided by the Department of Health and Wellness, various advisory bodies, and directed by government as a whole, sets direction, policy, and provincial standards that ensure quality healthcare services. One ‘advisory body’ is the Provincial Telehealth Committee (PTC) that plans strategic direction and provides overall provincial coordination to the Provinces telehealth project. Goals of the PTC are to integrate telehealth into mainstream clinical, educational, and administrative activities, and to collaborate among stakeholders for a province-wide network. The Department of Health and Wellness implements and ensures compliance with policy once it has been established.

As emphasised earlier, it is often difficult to consider any of the policy issues in isolation, since many single issues are confounded by aspects of others. Further, the 'inter-jurisdictional' nature of many of the issues is pervasive requiring that common solutions across jurisdictions be sought, rather than each jurisdiction considering and responding to an issue independently. Considering these statements, and earlier comments, the identified issues are clearly of 'relevance' to Alberta. Furthermore, it is reasonable to argue for the need for an appropriately resourced and central approach to facilitating e-health policy development in Alberta.

**Table IV. Roles, Responsibilities, or Mandates of Alberta Government Agencies \***

<b>Agency</b>	<b>Role, Responsibility, or Mandate</b>
<i>Minister of Health (MoH)</i>	<p>The Minister of Health and Wellness, aided by the Department of Health and Wellness, various advisory bodies, and directed by government as a whole, <i>sets policy for health care.</i></p> <p>The Mission Statement for the Alberta Health Care System is: "To maintain and improve the health and wellness of Albertans by <i>leading and working collaboratively with citizens and stakeholders.</i>"</p> <p>Two 'Core Businesses' are stated:</p> <ul style="list-style-type: none"> <li>• <b>Lead and support a system for the delivery of quality health services.</b> The Ministry <i>sets direction, policy and provincial standards</i> that ensure quality services. Key roles are to <i>set priorities</i> based on health needs, <i>determine the scope of financial, capital and human resources required</i>, and measure and report on the performance of the system.</li> <li>• <b>Encourage and support healthy living.</b> We support and encourage the wellness and health of Albertans through health promotion and protection programs, and disease and injury prevention programs that address risks to health where knowledge or early intervention can make a difference.</li> </ul>
<i>Alberta Health and Wellness (AHW)</i>	The Department of Health and Wellness <i>implements and ensures compliance with policy.</i>
<i>Regional Health Authorities (RHA's)</i>	The <a href="#">Regional Health Authority Act</a> requires each RHA to: 1) Promote health, 2) Respond to regional health needs (e.g. promote health services in a way that responds to the needs of individuals and communities and supports the integration of services and facilities in the region.), and 3) Report on performance.
<i>Telehealth Project</i>	<p>Objectives of the Provincial Telehealth Project are stated to be; a) <i>Integration of telehealth into mainstream clinical, educational and administrative activities</i>, and b) <i>Collaboration among stakeholders for a province-wide network.</i></p> <p>A primary group identified as involved in the Provinces Telehealth Project is the Provincial Telehealth Committee (PTC). Members of the PTC represent the Health Authorities, Alberta Wellnet, Medical Advisory Group to the Wellnet initiative and Alberta Health and Wellness. The Committee <i>plans strategic direction and provides overall provincial coordination</i> to the Telehealth project.</p>
<i>Electronic Health Record (EHR) Project</i>	No roles or responsibilities assigned, or mandate identified, for this Project

\* Taken from relevant official Alberta Health and Wellness websites

## 5.5 How should these issues be ranked?

It is recommended that addressing the identified issues should form the focus of e-health policy debate and formulation activities of Alberta Health and Wellness. It is doubtful that they can be tackled in any form of sequential order. But with the full application of privacy legislations<sup>7</sup> coming into force 1 January 2004, and the uncertainty that still surrounds their precise application to the healthcare arena, the issue of privacy protection must take precedence. Overall, it is considered the issues identified under Data Stewardship would have priority. But every effort must be made to allow AHW to transition itself into a proactive position in regard to e-health policy leadership and formulation, by encouraging informed debate and formulation of enlightened and appropriate policy. Concomitantly addressing issues identified under the three themes of Data Stewardship, Operational, and Inter-Jurisdictional will place AHW in a very informed and strong leadership position.

## 5.6 Limitations


It must be recognised that the issues identified in Table III were developed from the literature, and are not exclusive. Also, the methods adopted in this study to identify these issues were focussed (not systematic) literature searches, thus other issues within these themes may be identified with time or by other routes, and if appropriate should be incorporated into the current listings. Further, the rationalisation process for selecting the 34 e-health policy issues of relevance to Alberta, and the 16 of priority to AHW, was subjective and based upon expert opinion.

A further limitation is that each issue may have both deep and broad implications for various stakeholders, requiring careful and sensitive engagement and debate. These implications have not been addressed within this report. By way of illustration, the following example can be given:

A pragmatic concern exists over the continued provincial and national development of three distinct electronic records (the EHR, EMR (Electronic Medical Record), and EPR (Electronic Patient Record)), and the First Nations self governance structure restricting access to health information in their own electronic records. There are efficiencies and opportunities that arise with shared data resources, e.g. eliminating or minimizing the resource demands and inherent problems of managing separate, redundant data collections of like information. Other issues arise, such as acknowledgement as to which is the authoritative data set for data users. But at this time, concerns exist in various stakeholder groups about the overall issue of data stewardship (particularly if undertaken by the government rather than a third party).

New conceptual thinking and compromise is required on the part of stakeholders to find an effective and efficient solution that best serves the public, whether they are a patient

<sup>7</sup> For example: PIPEDA [*Personal Information Protection and Electronic Documents Act*] nationally; and PIPA [*Personal Information Protection Act*] provincially.



requiring 'illness care' or a citizen requiring 'wellness support'. Only open and transparent debate amongst all stakeholders will ensure this.

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## 6. Conclusion

The telehealth community is eager to develop comprehensive policies for telehealth in Canada. Advancement of e-health related policy in general, and inter-jurisdictional e-health policy in particular, will require that the potential consequences of policy options and directions be accurately foreseen, and that this information be used to inform and influence the policy process [Kemmm, 2001; Lavis et al., 2003]. This report provides focus for Alberta Health and Wellness by providing a limited number of policy themes and issues to pursue in the immediate future. Using this report, AHW can continue moving forward to identify potential consequences of policy options and directions, and use that information to inform and influence the e-health policy process in Alberta and elsewhere.

e-Health directly impacts issues of paramount concern to the public and across provincial healthcare systems. Its needs and directions require thoughtful, open and transparent debate by all interested parties. Within a clearly enunciated strategy, much broader input on the spectrum of key and sensitive e-health policy related issues should be achieved and open debate encouraged. This process would capture the thoughtful and insightful perspective of healthcare professionals and the public, as well as provide a 'social marketing' aspect that would smooth the way to integration of e-health into existing healthcare structures and processes.





## **7. Acknowledgements**

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## **9. Appendices**

**Appendix 1 Focussed literature searches**

**Appendix 2 National Telehealth Outcomes Indicator Project Workshop**

**Appendix 3 National Telehealth Research Summer Institute**

**Appendix 4 Actors Involved in e-Health Policy Development**

**Appendix 5 Rationalization of e-Health Policy Issues**

**Appendix 6 34 Rationalised and Re-Categorised e-Health Policy Related Issues**

## Appendix 1 Focussed literature searches

Two focussed literature searches were undertaken. First, a general search utilising PubMed (medical and scientific literature) and Google and Netscape ('grey' Internet-based literature), and second a review of the Telemedicine Information Exchange database. Both search strategies reflected the need to identify broad policies and issues that may be of concern to Alberta Health and Wellness (AHW). Telehealth and e-health policy issues that clearly fell outside of Alberta, such as global activities, were removed from this analysis.

### A. General Search

The following search terms were used when searching PubMed.

e-health	Telehealth	Policy	Guidelines
Alberta	Canada	Telemedicine	Regulations
Legislation (law)	Human Resources	Consent	Registration
Documentation	Licensure	Liability (risk)	Credentialing
Confidentiality	Reimbursement	Records	Training
Interoperability	Privacy	Integration	Funding
Security	Encryption		

The same key words were used for both the PubMed and on-line searches. The two main search engines used for on-line searches of the world-wide-web (www) were Google (a meta search engine) and Netscape.

### B. Telemedicine Information Exchange Search

This search linked the terms e-health, e-health, telehealth, or telemedicine with policy. The search was restricted to English language abstracts for publications (all types) published in the last 10 years (from 1993 to 2003). Search terms were: Telemedicine and telehealth, linked to policy.

## Appendix 2      National Telehealth Outcomes Indicator Project Workshop

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 indicators that could be used by the broader telehealth community when comparing or performing evaluations of telehealth applications.

A report is being prepared of the NTOIP Workshop presentations, breakout discussions, and re-convened 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: [www.ucalgary.ca/ntoip](http://www.ucalgary.ca/ntoip), 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 (COIs) 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 COIs 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.



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### Theme 3: Economic Evaluation

This presentation focused on the economic evaluation of telehealth applications, noting the pro's and con's of various models. Five main economic evaluation techniques were described, including 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 process, 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.

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

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 policy relevant areas of evaluation, outcome indicators, and dissemination.

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## **Appendix 3            National Telehealth Research Summer Institute**

The Health Telematics Unit at the University of Calgary hosted the fourth annual **Telehealth Research Summer Institute** (TRSI) at the University of Calgary on June 25 to June 28, 2003. The TRSI has become an annual event focusing on research and evaluation of telehealth / e-health programs and telelearning initiatives implemented into health care systems. TRSI 2003 participants included members from the public, private, and government sectors interested in moving e-health evaluation from practice to policy. TRSI participants were actively engaged in discussions around the evidence of telehealth / e-health impact and recommendations to move global e-health policy and research agendas forward. The themes that underscored TRSI 2003 were: evaluation frameworks, practice to policy, knowledge transfer, and global e-health policy and inter-jurisdictional strategies.

A report is being prepared of the TRSI 2003 presentations and small group discussions, as well as key insights. Additional supplementary information, such as presentation slides, will be posted on the Health Telematics Unit (HTU) website: [www.ucalgary.ca/telehealth](http://www.ucalgary.ca/telehealth) in early 2004. The report will be distributed to all TRSI participants and Canadian Society of Telehealth (CST) and COACH Board Members, and made available to telehealth coordinators and other CST members, public sector groups, University Departments with health informatics programs, industry leaders, and others through announcements or postings on appropriate websites (CST, OHIH, KUUC, and CHITTA).

### **Theme 1: Evaluation Frameworks**

Four presentations were made on the issue of e-health evaluation frameworks. The first presentation introduced the theory behind evaluation frameworks in general. The second, third and fourth presentations discussed a variety of evaluation frameworks, including the CHIPP Evaluation Framework, the Modified Donabedian framework, and an emerging framework. The strengths and weaknesses of each evaluation framework were highlighted.

### **Theme 2: Policy in Practice**

Four presentations were made on the issue of policy in practice. The first presentation focused on how we move from e-health practice to policy, by engaging the “people vehicle”. The final three presentations provided real life examples of how e-health policy is being practiced from provider, institutional, and network perspectives.

### **Theme 3: Knowledge Transfer**

The final presentation of Day Two focused on knowledge transfer. This presentation detailed methods of moving research into both policy and practice while illustrating the barriers to adoption of research.

### **Theme 4: Global e-Health Policy and Inter-jurisdiction Issues**

Four presentations were made on the final morning of TRSI 2003. The first presentation discussed the “Glocal e-Health Matrix”, as a way of describing how local events have global impact and vice versa. The final three presentations focused on the issues and challenges that exist around e-health policy as seen in Canada, the United States and Australia.

### **Priority Areas in Advancing Telehealth**

Issues related to: evaluation frameworks, knowledge transfer, practice to policy and global e-health policy provided the focus for the presentations and small group discussions throughout the TRSI 2003 Workshop. Key ideas and insights from discussions around such issues rounded out this thinking.

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## Overall Recommendations

A number of issues were raised in the Workshop, and the recommendations for their resolution are as follows:

- Communication is key. In order to move from e-health practice to policy and influence decision- and policy-making, we as researchers need to become apt at spotting opportunities and conveying our message clearly to a variety of audiences (known as knowledge translation/ transfer).
- There is no single evaluation method to be used when evaluating e-health applications. It is recommended that one should adopt a recognized but flexible evaluation framework and adapt it to one's needs. Making certain that the framework includes elements such as: global and societal perspective; common definitions and standards for indicators; and that the model follows the life cycle of the project.
- Education of decision makers, researchers, the public, and healthcare practitioners is vital in order to swiftly advance e-health integration and inter-jurisdictional e-health policy.

To advance inter-jurisdictional e-health policy, there is no easy-to-employ strategy. Any strategy will take great effort and time. Some strategies that will prove beneficial to e-health policy include: education; social marketing; creating a demand / expectations strategy; develop a knowledge warehousing strategy; and formulate a broad and collaborative strategy amongst stakeholders.

## Appendix 4      Actors involved in e-health policy development

### ***Advisory Committee on Information and Emerging Technologies (ACIET)***

Initiated in December 2002, this group has 5 identified priority areas: Emerging Technologies Assessment, Genomics, Pharmaceuticals Strategic Advances, Strategic Directions for a pan-Canadian Health Infostructure (includes Information Technology), and Privacy. Their mandate is to provide policy development and strategic advice on health information issues and on the effectiveness, appropriateness and utilization of emerging health products and technologies to the Conference of Federal, Provincial, and Territorial (F/P/T) Deputy Ministers of Health. ACIET's previous incarnation, the National Advisory Committee on Health Infostructure, viewed privacy, security, cost, reimbursement, licensure and the availability of consistent, high-quality, clinically relevant data as key issues.

### ***Alberta Government***

#### ***a) Alberta Health and Wellness***

The AHW 'Information Management and Information Technology Governance Council' (IM/IT Governance Council) has been created. This advisory executive committee has the mandate for the governance of IM and IT investments in the publicly funded health sector of Alberta. It provides strategic direction and tactical plans based upon sector-wide goals and priorities, and oversees the building, implementation, operation, and data stewardship of shared IM/IT investments. Under the IM/IT GC are currently three committees, the IM Committee, the IT Committee, and the EHR Data Stewards Committee. In addition, training has been mandated by Alberta Health and Wellness as a prerequisite to connecting to the provincial Electronic Health Record. The training includes confidentiality and privacy awareness.

#### ***b) Alberta Wellnet***

The Health Professions and Telehealth branch and Alberta Wellnet are involved with e-health activities and policy related issues.

#### ***c) Personal Information Protection Act (PIPA)***

Developed by Alberta as a means of superseding the federal PIPEDA (*Personal Information Protection and Electronic Documents Act*) legislation. Alberta's *Personal Information Protection Act* (PIPA) received Royal Assent on December 4, 2003 and the Personal Information Protection Act Regulation (A.R. 366/2003) was enacted on December 10, 2003). The Act and Regulation will come into force on January 1, 2004. It is unclear if PIPA has formally been accepted as '*substantially similar*' to the Federal PIPEDA legislation, and therefore can be considered to supersede the federal PIPEDA.

### ***Alberta Health Regions***

Development of a comprehensive information security policy for each Region is currently underway. Challenge in balance the need for information privacy training and security with the reality of day-to-day workloads and processes.

### ***Alberta Medical Association (AMA)***

The Alberta Medical Association has taken a lead role in framing the data stewardship debate from a health provider perspective within Alberta.

### ***Canada Health Infoway Inc. (CHII)***

Although not a direct mandate of CHII, its mission (fostering and accelerating the development and adoption of interoperable electronic health information systems on a pan-Canadian basis) will inevitably lead to its influencing e-health policy and policy formulation.

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

CIHI's mandate, established jointly by federal and provincial/territorial ministers of health, is to a) coordinate the development and maintenance of a comprehensive and integrated approach to health information for Canada; and b) provide and coordinate the provision of accurate and timely data and information required for establishing sound health policy; effectively managing the Canadian health

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system; and generating public awareness about factors affecting good health. CIHI's role in health indicators development (Roadmap Initiative), data collection, and standards development (coding and classification, MIS guidelines, Infostructure standards), mean CIHI is intimately involved in policy development. For example, its [National Public Key Infrastructure \(PKI\) Framework for Health](#) (a national framework for the secure communication of health information), defines the requirements to ensure confidentiality, integrity and authenticity of data when sharing health information electronically on a Pan-Canadian basis.

***Canadian Medical Association***

The CMA has developed an informative handbook (Privacy in Practice: A Handbook for Canadian Physicians). Other than this, a search of the CMA website for either telemedicine or telehealth individually or linked with policy produced no relevant hits.

***Canadian Medical Protective Association (CMPA)***

The CMPA has been active in issuing telehealth guidance through articles (CMPA, 2000; CMPA, 2002).

***Canadian Nurses Association***

The CNA released a position statement in 2001 that related to nursing practice and e-health (CNA 2001).

***Canadian Society of Telehealth (CST)***

At the CST's annual conference a breakfast roundtable discussion on telehealth policy issues recommended the formulation of a document outlining urgent policy issues (identified by the membership), placing these issues in priority, and sharing this information amongst CST members and with Health Canada. The intent is to develop national Task Forces and develop position statements.

***CANARIE Inc.***

CANARIE is Canada's 'advanced Internet development organization' whose mission is to accelerate Canada's advanced Internet development and use. This is achieved through facilitating the widespread adoption of faster, more efficient networks and the development of advanced products, applications and services to run on them. Although not directly mandated to develop policy, their influence on policy direction is clear (e.g. CANARIE 1999).

***COACH: Canada's Health Informatics Association***

COACH focuses on e-health technology, systems, and the effective use of health information for decision-making. In 2001, COACH published their 'Guidelines for the Protection of Health Information' which offers a framework to develop and implement security and privacy programs. COACH remains influential in policy development in this area.

***College of Family Physicians and Surgeons of Canada (CFPSC)***

This group (through their Computer and Health Information Programs Committee (CHIP)) has drafted statements on issues of special interest to family physicians: a) Privacy, confidentiality, and security; b) data stewardship and dialogue re data sharing; c) Cost; d) Health Information Quality. They want a National Health Information Privacy and Security Act – including a monitoring agency, and deterrents. They also argue that since 80% of patient data is located at the family physician level, then stewardship of the data should be located at that level, with health records being located on servers of small multi-disc groups of family physicians.

***College des medecines du Quebec (CMQ)***

CMQ has a comprehensive policy framework on 'telemedicine' (Hasham et al, in press).

***College of Physicians and Surgeons of Alberta (CPSA)***

This group has enacted the "Practice of Medicine by Telecommunication Across Provincial Boundaries" bylaw (in accordance with FMLAC recommendations) (CPSA 2000).

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### ***College of Physicians and Surgeons of New Brunswick (CPSNB)***

It has been reported that New Brunswick offers a "Courtesy License" for an out-of-province physician to directly communicate with a patient in the province (Hasham et al., in press).

### ***College of Physicians and Surgeons of Nova Scotia***

The CPSNS endorsed very brief 'Guidelines for the Provision of Telemedicine Services' in February 2001 (CPSNS, 2001).

### ***College of Physicians and Surgeons of Saskatchewan (CPSS)***

It has been reported that the bylaws of the CPSS address telehealth (Hasham et al., in press).

### ***Federal Government***

Canada has enjoyed considerable federal support for e-health, and the Federal government has been responsible for developing early perspectives on various e-health policy related issues. For example, through groups such as the Canadian Advisory Council for Health Infostructure reports or publications were developed on privacy and confidentiality (CANARIE, 1999), risks and liabilities (Robinson, 1998), reimbursement (Pong and Hogenbirk, 2000) and licensure (Pong and Hogenbirk, 1999).

Federal legislation on privacy exists that impacts e-health:

- Access to Information Act (Revised Statutes of Canada 1985, c. A-1)
- Personal Information Protection and Electronic Documents Act (PIPEDA) (Statutes of Canada 2000, c. 5) applies to personal health information collected, used, or disclosed in the course of commercial activities across provincial/territorial and national boundaries. (Comes fully into force 1 January 2004).
- Privacy Act (Revised Statutes of Canada 1985, c. P-21) applies to the public sector.
- Statistics Act (Revised Statutes of Canada 1985, c. S-19) applies to collected patient-identifiable health information.

The Information Commissioner of Canada has indicated that legislation is missing that deals explicitly and comprehensively with the creation of records and the government's stewardship of recorded information over its complete life cycle (OICC, 2003).

### ***Federal Healthcare Partnership (FHP)***

Established in November 2003, and succeeding the HCCI. A noted success of the HCCI was the value of exchange of information related to program management, which led to further partnership arrangements. Also, the pooling of policy expertise and experiences resulted in improved and more consistent evidence-based decision-making in some program areas. This in turn results in better support to Ministers. During 2002-2003, the HCCI partnership agreed to work together to address such complex issues as data security, privacy protection and linkages to provincial initiatives. It can be assumed the same approaches will be adopted by, and the same benefits will accrue to, the FHP, and therefore that they will be significant participants in e-health policy development.

### ***Federation of Medical Licensing Authorities of Canada (FMLAC)***

This group has developed very broad guidelines on telemedicine and suggested that the provincial licensing authorities develop specific telemedicine regulations.

### ***Health Care Coordination Initiative (HCCI) (see also Federal Healthcare Partnership (FHP))***

Established in 1994, the Health Care Coordination Initiative functioned to regroup federal departments that have health care responsibilities. Its existence is predicated on the belief that departments could reduce costs and improve service to clients by working together on issues of mutual interest by collaborating and facilitating the integration of federal infostructure initiatives into the broader pan-Canadian Health Infostructure activities. Member departments included Health Canada, Veterans Affairs Canada, Department of National Defence, Correctional Services Canada, Royal Canadian Mounted Police, Public Works and Government Services Canada, Canadian International Development Agency, Citizenship and Immigration Canada, Privy Council Office and

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Treasury Board Secretariat. This group was renamed as the Federal Healthcare Partnership in November 2003.

***National Initiative for Telehealth (NIFTE)***

NIFTE has examined and provided insight and recommendations regarding a number of telehealth related policy issues, including in the areas of organizational, human resource, technology and equipment, and clinical standards and outcomes issues.

***Office of Health and the Information Highway (OHIH)***

Created in 1997, OHIH is Health Canada's focal point for e-health, multi-channel government service delivery, and privacy issues. Their mandate includes working with other stakeholders to develop policies/guidelines, contribute to the development of standards, and provide strategic advice. OHIH Program Activities include ongoing development of the [Pan-Canadian Health Infostructure](#), [eHealth Resource Centre](#), [Canada Health Infostructure Partnerships Program \(CHIPP\)](#), [Canada Health Portal \(CHP\)](#), and [Protection of Personal Health Information](#). Issues identified as of importance include: electronic health record, integrated provider solutions, protection of personal health information, standards, telehealth, and change management.

***Ontario College of Physicians and Surgeons (OCPS)***

It has been reported that the OCPS offers no official guidelines or statements on 'telemedicine'. (Hasham et al., in press)

***Western Health Information Collaborative (WHIC)***

WHIC (and its sister groups across Canada) offer potential as a nexus for collaborative policy development.



## Appendix 5 Rationalization of e-Health Policy Issues

In order to rationalize and simplify the number of e-health policy issues identified, guiding principles and a conceptual framework were developed. Guiding principles were:

- possible redundancy or duplication should be eliminated, and
- individual 'issues' should represent distinct points or matters for public discussion and debate.

The conceptual framework (described below) was intended to maintain an Alberta focus. Using these tools, the listing of issues identified through the literature was reviewed and refined as described below. During this process three new policy 'themes' were identified (Data Stewardship, Strategic Support, and Inter-Jurisdictional). In this way a shortened listing of e-Health Policy Related Issues was developed, categorised by themes (Table III, Section 5.4). A final listing of *34 Rationalised and Re-Categorised e-Health Policy Related Issues* was developed (Appendix 6).

### Conceptual Framework

The e-Health ICT Impact Model was adapted to represent the Alberta setting, and to include a listing of creators and users of the Health Informatics and Telehealth components (Figure 3). This listing was considered to be identical for both creators and users.

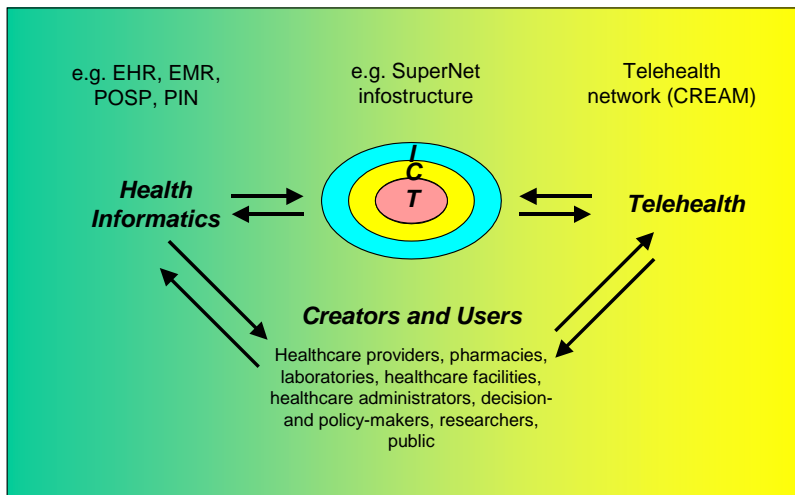


Figure 3. Adaptation of the e-Health ICT Impact Model to represent the Alberta setting.

included use of the Internet (e.g. interaction with patients), the world-wide-web (e.g. patient access to their own laboratory results), and remote monitoring (e.g. 'smart homes'; indwelling wireless physiological monitors for patients).

### Refining the number of e-Health Policy Issues

Upon review, some issues originally identified from the literature were considered to be either overarching goals or desirable strategic directions, and therefore not appropriately identified as single issues. Thus *access* was considered to be a component of *sustainability* (a sustainable system will encompass appropriate access), and *sustainability* was considered to be the single overarching goal of resolving all identified issues related to e-health. Both *access* and *sustainability* were removed as single issues. Within the conceptual model, some issues were linked with the ICT



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component. For example, a new theme of Data Stewardship was linked with Information; the issue of integration was linked with Communication, and the issues of standards and reliability (and theme of interoperability) were linked to Technology.

The final categorization of identified e-health policy issues into themes of relevance to Alberta is described below.

### **Theme: Professional**

*Malpractice* was transferred to this theme. When considering *inter-professional relationships*, the issue of clearly describing the *roles* of each professional group will be an integral activity, thus *roles* has been subsumed under *inter-professional relationships*. Other issues incorporated in this theme are; *licensure, certification, registration, and professional-patient relationship*.

### **Theme: Operational**

*Risk Management* and *Liability* have been subsumed as issues under 'Operational'. The issues of *organization of medical services, planning and coordination, and scope of practice* (each important issues) have been considered to be factors impacting *referral patterns* for access to and receipt of healthcare services, and have been subsumed under the single issue of *referral patterns*. *Ownership* has been assumed to refer to the private versus public debate, and has been considered akin to the issue of *control*; for this reason *control* has been subsumed under *ownership*.

Other issues incorporated in this theme are; *human resources, reimbursement, evaluation, business case, and funding*.

### **Theme: Institutional**

*Accountability* is now incorporated within 'Institutional'. According Pong and Hogenbirk, (1999) *credentialing* and *privileging* are the same, thus *credentialing* has been eliminated in favour of *privileging*.

Other issues incorporated in this theme are; *accreditation, responsibilities, training, and competence*.

### **Theme: Ethics**

The policy issue 'ethics' was removed, as it was already identified as a distinct theme. The ethical issues identified (*confidentiality; consent*) were considered fundamental principles underlying the entire healthcare process, not merely e-health applications. These were retained as issues under the theme of Ethics, since it was felt distinct e-health related resolution to these issues is required. The other issue originally identified under 'ethics' – *privacy protection* – was considered a specific aspect of '**Data Stewardship**', and transferred to this new category.

### **Theme: Legal**

This theme was removed. The rationale applied was that legal issues, debate, and legal challenge can arise for many of the other specific issues identified, therefore having a separate category was redundant. *Risk Management* and *Liability* were subsumed as issues under the theme of 'Operational'. *Malpractice* was transferred to the theme 'Professional', since it specifically refers to misbehaviour by a professional, and is typically handled by professional groups. *Accountability* was transferred to the theme 'Institutional'. Finally *Focal Point of Consultation* (also termed *Locus of Consultation*) was transferred to another new theme '**Inter-jurisdictional**'.

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## **Theme: Interoperability**

Because interoperability is identified as a theme, its identification as an issue is redundant, thus the issue of *interoperability* was removed. Within Interoperability two issues now reside: *standards*, and *reliability*.

## **New Theme: Strategic Support**

Some issues were regrouped and placed under this new theme of 'Strategic Support'. This theme now contains the issue: *Building ICT infrastructure* and *Development of networks*.

Because strategic support involves both public and private sectors, singling out of *Government support* as an issue was considered inappropriate, and was effectively accommodated under the two issues identified under Strategic Support. It was removed from the listing of issues.

## **New Theme: Data Stewardship**

Most organisations will already have informal levels of data stewardship and governance in their organizations. However, no formal definition of 'Data Stewardship' was located through a) searching websites of the Government of Alberta, Privacy Commissioner of Canada, Bill C-6 (PIPEDA), Bill 44 (PIPA), International Standards Organisation (ISO), Canadian Society of Telehealth (CST), American Telemedicine Association (ATA), and the International Society for Telemedicine (ISfT), b) searching on-line and published (European Commission Telemedicine Glossary) glossaries, or c) web-based searches on the term 'data stewardship'.

As a consequence, a working definition of *data stewardship* was formulated by considering the definition of a 'steward' (which is "one who manages another's property, finances, or other affairs"), and reviewing corporate and university web pages discussing stewardship of data. These sources indicate that a stewardship program should focus on improving data quality, reducing data duplication, and formalizing accountability for data.

Thus **Data Stewardship** has been defined in this report as:

*'Establishment of formalized processes to ensure trusted and reliable accountability of information assets (data), including the appropriate collection, quality, warehousing, networking, management, and control over access to specified and secure data.'*

Specific issues now grouped within the theme of **Data Stewardship** are: *privacy protection*, *documentation*, *data security*, and *information quality*.

## **New Theme: Inter-jurisdictional**

This concept was recently introduced (Scott et al., in press). Within the context of e-health policy debate, *jurisdiction* was described as a generic descriptive term for any identifiable 'unit' that possesses some autonomy in providing or presiding over healthcare services and activity within a defined sphere of authority (e.g. hospital, health region, administrative region, country, international agency). *Intra-jurisdictional* was described as activity within a single jurisdiction (e.g. single hospital or single health region), and *inter-jurisdictional* was recommended when referring to activity that taking place between one or more jurisdictions. Use of the term 'cross-jurisdictional' was discouraged since it implies bi-directional interaction and crossing of a single barrier or border. e-Health has the potential to cross many barriers and borders (and different types) in a single e-health transaction, which is better implied through use of the term inter-jurisdictional. Even cursory reflection on the policy issues identified above raises the potential for inter-jurisdictional impact of many, if not all, issues ('glocal' impact).

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Specific issues now grouped within this theme are; *Inter-jurisdictional billing*, and *locus of consultation* (formerly *focal point of consultation*). Note that the issues of *reciprocal billing* (a mechanism), and *inter-Ministry billing* (a specific example) are crucial issues to address if e-health is to perform efficiently and effectively, but both have been subsumed under *inter-jurisdictional billing*. Also grouped under **Inter-jurisdictional** is the theme of *integration*.

## Appendix 6

## 34 Rationalised and Re-Categorised e-Health Policy Related Issues

<b>Data Stewardship</b>	<b>Operational</b>	<b>Inter-jurisdictional</b>
<i>Privacy protection</i>	<i>Risk management</i>	<i>Inter-jurisdictional billing</i>
<i>Documentation</i>	<i>Liability</i>	<i>Locus of consultation</i>
<i>Data security</i>	<i>Referral patterns</i>	<i>Integration</i>
<i>Information quality</i>	<i>Ownership</i>	
	<i>Human resources</i>	
<b>Ethics</b>	<i>Reimbursement</i>	<b>Interoperability</b>
<i>Confidentiality</i>	<i>Evaluation</i>	<i>Standards</i>
<i>Consent</i>	<i>Business case</i>	<i>Reliability</i>
	<i>Funding</i>	
<b>Professional</b>	<b>Institutional</b>	<b>Strategic Support</b>
<i>Malpractice</i>	<i>Accountability</i>	<i>Building ICT</i>
<i>Licensure</i>	<i>Privileging</i>	<i>Development of networks</i>
<i>Certification</i>	<i>Accreditation</i>	
<i>Registration</i>	<i>Responsibilities</i>	
<i>Prof.--patient relationship</i>	<i>Training</i>	
<i>Inter-Prof. relationships</i>	<i>Competence</i>	

NOTE: The suggested themes are for convenience only, and a means to rationalise the issues identified. They DO NOT imply exclusivity over the consideration, debate, or resolution of any issue. Indeed, as noted earlier, it is often difficult to consider any of the policy issues in isolation (a single issue can be confounded by aspects of one or more others). Furthermore, the 'inter-jurisdictional' nature of many of the issues is pervasive, which will require that common solutions across jurisdictions be sought, rather than each jurisdiction considering and responding to an issue independently.