Vision 2020 Workshop on

Children's Health Care

Toronto, Ontario

Office of Health and the Information Highway
Health Canada

January 24, 2000

Our mission is to help the people of Canada
maintain and improve their health.

Health Canada

Table of Contents

PREFACE

Harnessing the power of modern information and communications technologies (ICTs) to health care entails such innovative applications as electronic health records (EHRs), telemedicine, telehomecare, and Internet-based information for the health care professional and consumer alike. These applications are emerging as an enabling feature of national importance for transforming the Canadian health system in the 21st century and contributing to Canadians' health. They can significantly improve the accessibility and quality of health services for all Canadians, while increasing efficiency of the health system.

The Office of Health and the Information Highway (OHIH) was created in recognition of the growing importance of information and communications technologies in health and health care. The Office is Health Canada's focal point for all matters concerning the use of ICTs in the health sector. Areas of responsibility include developing and implementing major network systems, managing incentive programs, policy development, knowledge exchange and consultative and collaborative efforts with key stakeholders, including provincial and territorial ministries of health.

The objectives of OHIH are (1) to provide a national leadership role in the development of the Canadian Health Infostructure; (2) to encourage change through better information, objective communications and effective partnerships; and, (3) to influence key decision makers to make better informed decisions and work collaboratively in the development and application of information and communications technologies.

Within this strategic framework, OHIH envisions an integrated health care system, a system providing continuity of care through all stages of delivery and across all points of care for all Canadians. In addition, the Canadian Health Infostructure will ensure that all points of care are networked in a safe and secure way; a national system of electronic health records is fully implemented; and telehealth services are available for all. For more information, readers are invited to visit the OHIH web site at: http://www.hc-sc.gc.ca/ohih-bsi/

In keeping with its strategic objectives, OHIH is consulting with key stakeholders in order to further define the vision for a Canadian health infostructure until the year 2020. One way of accomplishing this is to hold Vision 2020 workshops whose objectives are: to describe the vision of the ideal health system in the year 2020 and the role that ICTs will play in that system; to discuss challenges and opportunities for realizing this vision; and to identify concrete next steps that could be taken at the federal, provincial, territorial, regional and individual organizational levels to promote ICT use.

This report is based on one such workshop held in Toronto, Ontario in January, 2000. Several additional such workshops are planned for the year 2000 with other stakeholders, including physicians, nurses and health care administrators.

EXECUTIVE SUMMARY

A one-day workshop on the vision of children's health care in the year 2020 and the role that information and communications technologies (ICTs) will play in that system was organized by the Office of Health and the Information Highway (OHIH), Information, Analysis and Connectivity Branch, Health Canada in January, 2000.

Twenty-eight child health professionals with a strong interest in ICT use in health care were invited to participate.. The participants represented the Canadian Pediatric Society, the Canadian Pediatric Nurses Association, pediatricians, pediatric surgeons, pediatric intensivists, pediatric nurses, child health/telehealth network administrators and child health researchers from pediatric hospitals and general hospitals with a significant pediatric care component. (See Appendix A.)

New and emerging ICTs, such as telehealth and electronic health records, will dramatically change the way children's health care is delivered both in the near and distant future. Participants were asked to explore the *possibilities* for ICTs to shape the health care system in ways that will improve the quality of, enhance access to and increase the efficiency of health care to Canadian children. Their deliberations followed three stages.

First, participants were asked to reflect on their **vision** of an ideal children's health care system in 2020, and the role ICTs will play. For example, should we be striving to make the child the focus of the health care system? How could ICTs help to make this happen? What contribution will telehealth and electronic health records make to children's health care?

Next, participants were asked to consider the **opportunities** to realize their vision and the **challenges** that must be overcome to get there. For example, does the current organization of the system represent a challenge - or an opportunity? Privacy is often mentioned as a challenge. Can ICTs offer an opportunity to address privacy and confidentiality concerns?

Finally, participants were asked to develop an **agenda for action**. Given the vision that we want to achieve, and the challenges and opportunities identified, what concrete actions would be required now, and who should take these actions?

This report attempts to recapture the many thoughts and ideas expressed by the participants during the workshop.

OPENING REMARKS

Andrew Siman, Director General of OHIH, welcomed participants to the workshop. He highlighted the fact that health care is the number one issue among Canadians, and that ICTs in health care have been identified as one of the priorities of Health Canada. He indicated that health care is becoming increasingly information intensive from all perspectives, from the health professionals to the general public, and ICTs are becoming an increasingly vital element of the health system.

Mr. Siman outlined the history of, and funding for, the Office, as well as the key strategic directions and activities of OHIH. He suggested that the OHIH's challenges ahead will involve:

   - shared visions and shared commitments;

   - consensus building, collaborative approaches and effective partnerships;

   - building a common understanding, awareness raising and education;

   - better information, and better sharing of information and knowledge;

   - the need to be driven by the longer-term perspective, while delivering on short-term results;

   - the need to focus on national priorities; and,

   - the need to engage stakeholders.

Mr. Siman challenged the participants to explore their vision of an ICT-supported children's health care system, and how we could go about achieving that vision. He indicated that this is the first in a series of vision workshops with various groups of key stakeholders, to seek a shared vision (and agenda) for the Canadian Health Infostructure. The proceedings of this and similar workshops will be shared within Health Canada and with provincial and territorial colleagues. The recommendations will be taken into account as we develop OHIH's plans for the coming years.

VISION

Participants were asked; "What is your vision of the children's health care system in the year 2020, and of the role that ICTs will play in that system?" Their responses can be grouped into seven key themes:

1. Child and family-centred health care system

There will be a shift in focus of children's health from intervention to prevention, beginning at preconception. This shift will encompass both prevention issues and medical issues, and will involve both medical practitioners and social services professionals. Health care issues will be seen from the perspective of the child and family as well. The vision of a child/family-centred health care system can be stated as "Healthy children in healthy homes in healthy communities".

An ICT-supported children's health care system (with the availability of such services as teleconsultation) will provide alternatives to seeking care outside of the community of residence. Since more care will be available to children in their home or community, there will be less family disruption.

Children who must remain in hospital for prolonged periods of time will remain connected to their families and schools, thereby facilitating their reintegration into the home and community.

2. Integrated health care delivery system

An ICT-supported child health (including mental health) care system will seamlessly link all points of care. Homes, schools, family practitioners, community clinics and urban hospitals will be connected to one another, thereby reducing the likelihood of children "falling through the cracks". Since the spectrum of care available to children and families will be interconnected, children will be able to quickly arrive at the best place for them along the continuum.

There will be improved coordination of care by health care providers both within and between communities. Geographic barriers to medical expertise will be erased. Children/families in rural and remote unique communities, such as First Nations communities, will have access to care by specialists and even specialized interventions from afar. "Just in time" information will be available for referrals.

Children with developmental delays will be evaluated in their own environments. Not only will this improve the validity of the assessments, but may serve to keep the child out of the "system" as long as possible (i.e., children will be able to get the help they require in their own community).

3. Comprehensive clinical information accessible only to those with a need to know

Children/families will own and control the access to their EHRs, including their own access to their records. It is recognized that this control and access may influence to some extent the comprehensiveness of the record, since children/families may not wish to have certain aspects of their medical history contained therein.

They will not have to repeat their medical history to a succession of practitioners. Information taken by one health care provider will be available in digital format to any other health care provider who *needs to know* and to whom the patient has given consent.

Medical tests and other interventions will not be duplicated since results will be available on line. Moreover, practitioners will better understand family health trends, through the linkages of EHRs of siblings and parents.

Privacy legislation will ensure the confidentiality of the patient record, while at the same time not unduly limiting the sharing of information among those practitioners who would be granted access by the child/family. Both privacy legislation and policies and procedures to ensure confidentiality will be continually monitored and amended as necessary. The public will come to realize that mechanisms to ensure confidentiality as well as new technologies will make EHRs more secure than current paper records.

In building the EHR, every effort will be made to build on existing methods of collecting information so as to minimize the difficulty in converting to a new system.

4. Research

EHRs will be an invaluable resource for health researchers, who will use privacy-protected, aggregated data to investigate trends, evaluate treatments, locate optimum points of intervention in developing children, and suggest ways to prevent illness and disabilities from even before conception.

There will be uniform, discipline-specific standards for entering and interpreting the data contained in electronic health records.

5. Reliable health information available to all Canadians

Credentialed health information will be available to children/families online via the Internet. This information will assist them in maintaining and improving their health, and will enable children/families to participate more fully in decisions about their health and the health care they receive no matter at what stage of life they are. Parents will be able to connect with other families with similar health concerns.

Children/families will have real-time access to services such as teletriage that will prevent unnecessary encounters with the health care system or suggest more appropriate ways of dealing with a particular health issue.

Health care practitioners will have a large body of easily accessible information which will support clinical decision making, as well as their continuing education.

6. Sustainability

The cost-effectiveness of ICTs in the health care system will be empirically demonstrated and funding to maintain ICT-supported information and delivery systems will be entrenched.

Practitioners will be reimbursed for participating in ICT-supported health care services, such as telemedicine and teleconsultation.

7. Infrastructure

The raison d'être of technology in health care will be to add value, build capacity and support people. The use of technology will be maximized to help achieve the vision of a child/family centred health care system.

The components of the technological framework of an ICT-supported child health care system, such as computers, scanners, cameras, video and audio platforms, cable wires, satellites and optical fibres, will be in widespread use. Health care consumers will be confident of the capabilities of these tools in the hands of competent professionals, as well as in their own capabilities in using new technologies such as Internet-based health information systems.

Practitioners will have access to user-friendly, non-threatening technology. The development of new technologies will be driven by client needs, rather than by industry.

Health professionals will be graduate from their professional programs skilled in the use of ICTs relevant to their discipline.

Telecommunication rates all over the country will be affordable.

CHALLENGES/OPPORTUNITIES

Participants were asked: Given the vision that you outlined, what are the challenges to be overcome in order to attain this vision? What opportunities do you see that would allow the vision to be realized? For example, does the current organization of the system represent a challenge - or an opportunity? Privacy is often mentioned as a challenge. Can ICTs offer an opportunity to address privacy and confidentiality concerns?

Overcoming the challenges associated with the uptake of ICTs in health care represents an enormous opportunity to improve the quality of health care for Canadian children, and ultimately, to the Canadian population. Our understanding of health care issues will be continuously improved, and our ability to shift from an interventionist "medical model" of health care to a preventative approach focussed on the determinants of health will be strengthened.

There is a powerful opportunity for the health practitioners and administrators present at this meeting to use their knowledge and position to bring this vision before communities and politicians. The vision will be successful only when it has grassroots support.

Child and family-centred health care system

An ICT-supported health care system can have a tendency to become depersonalized. There may be an opportunity for a new type of health professional, the health advocate, who could assist children and families to overcome this challenge in ways that are culturally appropriate.

Children/families have the opportunity to become more knowledgeable about healthy practices and their own health, and will be better positioned to be involved in decisions about their own health.

By bringing previously unavailable health care services into the community, the psychological stress and societal costs of separation (e.g. transportation and accommodation costs), for both children and families, will be greatly reduced.

An integrated health care delivery system

At this time, many rural and remote communities - the communities that will benefit the most from an ICT-supported child health care system - do not have reliable access to the Internet or to sufficient bandwidth to support widespread ICT use in health care. In many parts of the country, telecommunication rates are very high. As well, personal access to the Internet is not widespread across Canada, limiting the accessibility of electronic health information to families.

Among health professionals there is a hierarchy of attitudes and roles. However, the full potential of ICTs will only be realized when health professionals share information and decision-making. ICT-supported child health care has the potential to break down traditional hierarchies and patterns of decision-making among health care professionals.

Comprehensive clinical information available only to those with a need to know

There is currently a lack of national policies and standards concerning the privacy and confidentiality of the electronic health record. These are necessary to ensure that the information does not become accessible to commercial enterprises, for example, insurance and pharmaceutical companies.

There is an opportunity develop public confidence in such technology by improving privacy, security and access policies. Clear principles must be established to determine who has access to health records, and under what conditions. Protocols must be established for auditing health record transactions. The opportunity to determine what core data should be contained in the electronic health record, and how best to collect it, is also present.

Research

To ensure health records contain reliable and valid information, standards for collecting information need to be developed. There will likely be resistance to imposing a standard national protocol for collecting health information, since institutions and even groups within institutions have tended to build their individual databases to serve their unique purposes. This provides the opportunity to build software programs that can "translate" data from various databases into a common format.

Reliable health information available to all Canadians

Children/families are becoming ever more knowledgeable about their health and health care in general, due to the wide availability of health information afforded by the Internet. They will be more likely to query and challenge health care practitioners, perhaps on the basis of non-credible information. However, ICT technologies bring with them the opportunity to empower children and families, bringing them squarely into the decision-making process.

Sustainability

Patient expectations of the health care system, and of health care practitioners will likely increase dramatically as the uptake of ICTs in the health system increases. These expectations may surpass the capacity of the system to fulfil them. This will be especially significant as the population ages and demands more in-home and in-community care.

The presence of reimbursement policies for ICT-supported services such as teleconsultation varies widely among provinces. In addition, there are no country-wide policies for cross-province reimbursement. Clearly, for physicians to participate in an ICT-supported child health care system, health insurance plans will have to adjust to cover both ICT transactions and the preparation that is often required to participate in them.

There will be significant costs associated with implementing an ICT-supported child health care system for children related to:

- infrastructure development and purchase
- database development
- training
- business process and protocol development
- research
- communications
- practitioner remuneration.

Initially, cost-savings will not accrue to those who bear the costs, since the cost savings will be primarily societal (travel, accommodation). However, there is an opportunity to develop public-private partnerships to offset these costs and achieve economies of scale with, for example, telecommunications or utility companies. However, these partnerships may be viewed negatively by the public. There is also the opportunity for more sharing of resources among providing institutions.

Infrastructure

Compatibility and interoperability among various types of technology will need to be achieved. Another challenge will be to develop an adequate technology infrastructure in rural and remote communities.

Many health professionals currently in practice are not skilled in the use of ICTs. The opportunity exists to train a new generation of ICT-savvy health care practitioners by building such training into the professional education curricula. ICTs themselves can support a learning environment for the current generation of health professional, who can develop skill through distance learning.

ACTION PLAN/NEXT STEPS

Participants were asked: What should our be our agenda for action to realize the vision? Given the challenges and opportunities identified during the previous session, and the vision that we want to achieve, what concrete actions would be required now? And who should take these actions?

An ICT-supported child health care system will be realized through the collaborative efforts of practitioners, governments, public sector institutions and the private sector. Specialists, general practitioners, nurses and other health care professions will have to see the advantages of an ICT-supported child health care system to their patients and practices. Governments will have to respond financially in the short term to the prospect of long term cost benefits to the health care system. A critical success factor will be the willingness of provincial governments to include ICT-supported initiatives as insured interventions. Professional schools will have to begin training students to work in the technological and democratic context of an ICT-supported system. Hospitals, clinics and private practices will have to invest in the infrastructure required to participate in the system. And the private sector will have to invest in the development of hardware and software that will be the backbone of the infrastructure.

No one group is likely to act alone. The migration towards an ICT-supported child health care system will begin among small groups of cross-sectoral collaborators. Demonstrated successes will lead to more investment and collaboration further afield. Once initial success in these areas is demonstrated and communicated to Canadians, they too will realize the benefits of an ICT-supported child health care system.

Integrated health care delivery system

- Move the pendulum toward acceptance by the public of ICT use in health care by marketing to local (municipal and regional) governments and communities. Champions could include health professional organizations, for example family practitioners who could benefit from having access to pharmacy or local hospital records. User groups such as persons living with cancer or diabetes, could advocate for telehomecare, for example.

Comprehensive clinical information (EHRs)

- Promote the adoption of a national (universal), unique EHR identification number for every individual health record, so that various modules of a person's health record can be linked to one another

- Build the capacity to translate existing databases to a common information platform. This will ensure that institutions will not have to convert to a database structure that does not conform to their all data collection requirements.

- Establish an F/P/T Working Group to develop guidelines for the security and confidentiality of electronic health records. Ensure that the patient retains ownership of, control of , and access to their own health record. Develop national legislation allow health record information in digital format to be shared among health professionals, with patient consent and in a way that protects patients' privacy. Such legislation should permit the portability of EHRs between hospitals and provinces. Learn the lessons from provinces that are already engaged in drafting such legislation (e.g., Manitoba, Alberta, Quebec).

- Develop technologies, such as PKI (Public Key Infrastructure, an electronic signature), that will ensure that only authorized individuals can access an EHR.

Sustainability

C Apply evaluation frameworks to ICT initiatives to demonstrate their costs, benefits and effectiveness in health care delivery.

C Develop a national inventory of current Canadian and international initiatives that use ICTs to benefit child health - this will serve as a source of best (and worst) practices. Launch this information on an Internet web site.

C F/P/T governments need to develop a consensus on the priorities related to ICT use in health care, and develop a coordinated plan of action. For example, where can ICTs contribute to common priorities in health care for children and families? They should also develop national policies concerning reimbursement, liability and licensing.

C Move the pendulum towards acceptance of ICTs in health care by increasing public awareness, overcoming suspicion and building trust. Demonstrate how technology

can enhance privacy, rather than erode it, and how technology can reduce duplication of medical interventions. Publicize success stories in media. Involve all levels of government from municipal to federal. Need national leadership in selling the vision, breaking down silos between levels of government, and in developing a marketing strategy. Identify champions from among health care professionals, user groups (e.g. cancer patients), universities (re: training/education of health care providers) in selling the vision and obtaining buy-in. Demonstrate how ICT use can help address current crises in health care system (e.g. manpower issues).

C   Develop an F/P/T agenda based on ways in which ICTs can contribute to common priorities in health care for children and families, for example, moving health care closer to homes and away from institutions. Involve industry, primary care providers and public health in the further development of a longer-term vision (year 2020) and a short-term plan of action.

C   Find an area where a significant number of F/P/T agendas align and develop a large-scale demonstration project in a field that will appeal to all Canadians (e.g. in the field of cardiology or oncology). This will help to establish a business case for initiatives such as telemedicine, and will yield valuable lessons and promote successes. Health Canada could act as facilitator. Seek federal-provincial-territorial and private sector support for this project (build partnerships).

Infrastructure

C   Encourage schools that train health practitioners to teach students to use ICTs and work in an ICT-supported environment. Introduce training in ICT use into the first year of the programs.

C   Develop funding arrangements for local infrastructure (hardware, software) and technical support. Forge partnerships with industry, telecommunications and utilities companies for sharing infrastructure and obtaining economies of scale.

CLOSING REMARKS

Mr. Siman closed the workshop by thanking the participants for offering their valuable time, recognizing their very busy professional lives.

He noted the high degree of enthusiasm for encouraging the use of ICTs in health care. He undertook, on behalf of OHIH, to maintaining the momentum generated by the workshop, and stressed the importance of continuing the dialogue among ICT champions. The best way to progress is by "starting small" and demonstrating successes. ICT successes need to be brought to the attention of the public at large, for example, through the media. The concerns that applications, such as telehealth, will drive up health care costs need to be addressed through thorough evaluations of such initiatives.

APPENDIX A - WORKSHOP PARTICIPANTS

Chairman

Mr. Andrew Siman, Director General
Office of Health and the Information Highway, Information, Analysis and Connectivity Branch
Health Canada, Ottawa, ON

Break-out Group Facilitators/Recorders

Ms. Janice Hopkins, Director, Knowledge and Policy Development Division
Office of Health and the Information Highway, Information, Analysis and Connectivity Branch
Health Canada, Ottawa, ON

Mr. Jerry Lee, Director, Infostructure Systems Management Division
Office of Health and the Information Highway, Information, Analysis and Connectivity Branch
Health Canada, Ottawa, ON

Ms. Linda Senzilet, Senior Policy Advisor, Knowledge and Policy Development Division
Office of Health and the Information Highway, Information, Analysis and Connectivity Branch
Health Canada, Ottawa, ON

Participants

Dr. Jill Barter, Pediatric Intensivist
Charles A. Janeway Health Centre, St. John's, NF

Dr. Kathryn Bigsby, Pediatrician
Queen Elizabeth Hospital, Charlottetown, PEI

Dr Guy Bisson, Directeur, Télésanté
Centre Universitaire Santé L'Estrie, Site Fleurimont, Sherbrooke, QC

Mr. Wayne Boyce, Coordinator, MB TELMED
Children's Hospital of Winnipeg. Winnipeg, MB

Dr. Anne Canning, Pediatrician
Moncton Hospital, Moncton, NB

Dr. Roderick Canning, Neonatologist
Moncton Hospital, Moncton, NB

Mme Suzanne Coulombe
Hôpital Sainte-Justine, Montréal, QC

Dr. John Edmonds
Canadian Pediatric Society, Ottawa, ON

Mr. Bruce Ferguson, Head, Community Systems and Interventions
The Hospital for Sick Children, Toronto, ON

Dr. Robert Filler, Medical Director, Telehealth and External Medical Affairs
The Hospital for Sick Children, Toronto, ON

Dr. Frances Harley, Pediatric Nephrologist
University of Alberta Hospital, Edmonton, AB

Dr. Robert Issenman, Pediatric Gastroenterologist
McMaster Health Sciences Centre, Hamilton, ON

Dr. Frank Jagdis, Chief of Pediatrics
Queen Alexandra Centre for Children's Health, Victoria, BC

Ms. Kathy Kastner, President/CEO
The Health Television System Inc., Toronto, ON

Ms. Karen Levesque, Telehealth Coordinator
Saskatoon District Health, c/o Medical Affairs
Royal University Hospital, Saskatoon, SK

Mr. Ronald Lindstrom, VP Planning & Network Development
Children's & Women's Health Centre of BC, Vancouver, BC

Ms. Heather McCormack, Childhood and Youth Division
Health Promotion and Programs Branch, Health Canada, Ottawa, ON

Ms. Kellie McLean, Pediatric Nurse
Regional Hospital Centre, Bathurst, NB

Dr. Cecil R. Ojah, Chief of Pediatrics
St. John Regional Hospital Facility, St. John, NB

Dr. Tracey Parnell, Pediatrician
Cranbrook Health Council, Cranbrook, BC

Dr. Ray Postuma, Pediatric Surgeon, Director of MB TELMED
Children's Hospital of Winnipeg. Winnipeg, MB

Dr. Carl Robbins, Chair, TETRA/Telemedicine
Memorial University of Newfoundland, St. John's, NF

Ms. Sheila Ross, Director, Maritime Health and Partnership Development
Izaak Walton Killam Hospital, Halifax, NS

Dr. Kathy Speechley, Epidemiologist
Child Health Research Institute
Children's Hospital of Western Ontario, London, ON

Mr. Andrew Szende, CEO, Electronic Children's Health Network
c/o The Hospital for Sick Children, Toronto, ON

Dr. Gordon Tait
Canadian Pediatric Society, Ottawa, ON

Dr. Andrew Wade, Pediatric Nephrologist & Director of Dialysis
Alberta Children's Hospital, Calgary, AB

Ms. Olive Wahoush, Child Health Network Liaison
St. Joseph's Health Centre, Toronto, ON

Ms. Margaret Waligora, President
Canadian Association of Pediatric Nurses, Acton, ON

*Proceedings prepared by***:**
Janice Hopkins
Linda Senzilet
Alan Sobel