

National Indian & Inuit Community Health Representatives Organization

IN TOUCH

FIRST NATIONS & INUIT HEALTH INFORMATION SYSTEM: *ARE WE READY FOR TECHNOLOGY?*

by Heidi J. Kuran



Healthcare spending rises every year in Canada. The way healthcare is managed will need to change to become modernized, increase effectiveness and lower costs. How can we do this? Using technology for healthcare at the community level may be the answer. Technology will never replace the knowledge and compassion of a caregiver or CHR, but it can improve and extend the delivery of services. It can also offer a cheaper solution over the long run.

Healthcare is a complex and labour-intensive business. Every visit to a doctor creates many new pieces of paper. All of this complexity means that doctors, nurses and CHRs often spend as much time filling out paperwork as they do caring for patients. There are now many helpful computer programs for healthcare providers. Technology helps areas to access important health information in isolated. The Internet is also used now to gain knowledge. For example, using technology solutions, local doctors can get in touch with specialists anywhere in the world, day or night, to share their knowledge and have them examine patients from a distance. These techniques will greatly increase a patient's chances of recovery.

Medical record-keeping is one of the more time-consuming and expensive parts of the health care industry. Technology can effectively simplify how we do things. We often use solutions that are paper-based. We write a lot of information down. Using technology in record-keeping means that you can bring a patient's entire medical history into a computer and save it in a common place called a database. Having information in one place reduces errors and data loss. Now, trusted people such as doctors, nurses and CHRs have easier access to information. Computers have built-in security that keeps patient information private and secure. The doctor-patient relationship is changing. Individuals rely less on their doctor as their only source of health information. There are now more ways to share information among healthcare teams. In the future, technology will bring expert care to even the most remote and isolated parts of the world. Patients will be able to interact with the healthcare providers they need from any location, at any time. Individuals will have greater control over, and access to, their own medical information. (2)

TECHNOLOGY AND FIRST NATIONS COMMUNITIES

Is technology affecting healthcare in First Nations communities? The answer is yes, thanks in part to the First Nations & Inuit Health Information System. FNIHIS is an easy-to-learn community-based computer system. It provides CHRs and other healthcare professionals with a valuable tool for accessing client health data. The FNIHIS is comprised of 12 systems.

These systems can collect basic client information such as names, addresses and phone numbers. It can also collect information about immunizations, reportable diseases and chronic diseases. These systems create a set of health facts. These facts will help develop ways to improve health in First Nations communities across Canada. The FNIHIS is also a valuable tool to help track illness and disease trends specific to First Nations and Inuit communities.

There are **several barriers** to using a system like the FNIHIS in communities. They are:

POOR COMMUNICATION INFRASTRUCTURE

FEAR OF TECHNOLOGY AMONG FRONTLINE HEALTHCARE WORKERS

INADEQUATE OR LACK OF TIME FOR TECHNOLOGY TRAINING

OWNERSHIP AND PRIVACY OF DATA ISSUES

MISTRUST OF GOVERNMENT AND AGENCIES THAT CAN MISUSE HEALTH DATA

LACK OF LEADERSHIP FOR IMPLEMENTING THE FNIHIS

FNIHIS IS EXPENSIVE AND ITS BENEFITS UNCLEAR.

INTEGRATING FNIHIS INTO CURRENT HEALTHCARE PROCEDURES IS A COMPLEX PROCESS

POOR COMMUNICATION INFRASTRUCTURE

First Nations communities are spread across Canada and can be rural, urban, isolated, or northern. Within these communities, the access to modern technology differs in each area. Communication infrastructure includes things like telephone access, fibre optics for running Internet technologies and whether or not computers are used daily for work. Remote and isolated communities, especially in the northern regions, have a harder time accessing modern technology.

Isolated communities have a hard time because they often do not have the same technology advantages as big cities. Isolated areas may not have the same opportunities to get up to date information. They may not even have access to computers or the Internet.

In 1995-96, Health Canada gathered information on health from Canadians in what was called the National Forum on Health – Report on Dialogue with Canadians. Health Canada wanted to learn what problems remote and isolated communities face when trying to access health information. Health Canada got many revealing comments from the people they interviewed. Basically, people want equal access to appropriate healthcare information – the same access as in cities. Some of the comments from the forum were:

“Every individual life in isolated communities is worth as much as an individual life in the south.” (Iqaluit)

“The hospital [in Iqaluit] has help for French-speaking people but we don’t have the same level of service for us in Inuktituk. At least information on vitamins and prescriptions should be in your own language. There is an information centre in Nunavut for medical information including traditional measures and information on side effects.” (Iqaluit) (3)

In addition, in May of 1998, the Government of Canada conducted what was called a Rural Dialogue Session in Hay River, Northwest Territories. They brought in two groups: one group from Nunavut and the other from the Northwest Territories. The groups discussed community challenges in their northern and isolated communities. One of the biggest issues common to these two groups was lack of access to information and to the technology needed to feel on a par with the cities. There is often a general feeling that the government does not address the needs of the northern, rural and isolated communities. Isolated communities feel that the government needs to learn about the north. There is a need for rural, remote and isolated communities to be recognized in Ottawa. Ottawa must remain interested in the health information issues present in remote communities. (4)

The groups were asked the following question: What are the biggest challenges that you, your family and your community face as you look to the future? The group from the Northwest Territories cited as a challenge poor access to technology and a very slow introduction of Internet in remote or isolated communities. They also felt that getting onto the Internet and finding anything of value takes too long. This prevents people from getting involved in addressing issues to help their leaders. The group from Nunavut said that their access to the Internet was unreliable. Overall, community goals are to drastically increase communication access in isolated areas. (5)

To address the needs of rural and isolated communities, Industry < Canada is working on improving access to the Internet. The Community Access Program (CAP) helps to provide rural, remote and urban communities with affordable Internet access. The program also provides new ways to communicate and learn new things in today’s technology-based economy. The CAP is currently working to hook up 5,000 of Canada’s rural and remote communities to the Internet. There are so many communities where basic physical access to single phone lines is still a barrier. These communities face issues of reliable Internet connections and the high cost of providing communication equipment because they are not near a bigger town or city | where it might be cheaper. By working with provincial and territorial governments, educators, libraries, schools and the private sector, the CAP program aims to create up to 10,000 public Internet access sites in Canada by March 31, 2001. (6)

THERE ARE MANY REASONS WHY INDUSTRY CANADA CONSIDERS THAT TECHNOLOGY ACCESS IN RURAL AREAS SHOULD BE IMPROVED:

HELPING RURAL BUSINESSES OBTAIN ACCESS TO INFORMATION, CLIENTS AND MARKETS.

PROVIDING RURAL RESIDENTS WITH READY ACCESS TO PROGRAMS AND SERVICES.

HELPING PROVIDE EDUCATION, TRAINING OPPORTUNITIES AND SKILLS UPGRADING.

PROVIDING NEW APPLICATIONS IN AREAS SUCH AS RURAL HEALTH CARE.

Access to information and Internet service is a necessary requirement for residents to effectively participate and contribute within our society. It is very important for First Nations people to have access to their own health information. (7)

According to the Office of Health and the Information Highway - Health Canada, "it is paramount that there be universal, affordable, equitable access throughout Canadian society to the Canada Health Infoway."

To this end, the federal government should continue to ensure universal, equitable and affordable access to basic telecommunications infrastructure, now and in the future. Health Canada should also take a leadership role in ensuring that health information and healthcare applications for the public are developed to be accessible to all citizens, irrespective of their geographic location, income, language, disability, gender, age, cultural background, or level of traditional or digital literacy." (8)

FEAR OF TECHNOLOGY

"Traditional people of Indian nations have interpreted the two roads that face the light-skinned race as the road to technology and the road to spirituality. We feel that the road to technology ... has led modern society to a damaged and seared earth. Could it be that the road to technology represents a rush to destruction, and that the road to spirituality represents the slower path that the traditional native people have travelled and are now seeking again? The Earth is not scorched on this trail. The grass is still growing there." (Commanda 1991). (9)

"Aboriginal health care workers' unfamiliarity with and fear of technology is an effective barrier that impedes them from attaining basic computer skills that would enhance understanding and comfort levels with this technology." (Assembly of First Nations, November 1998). (10)

Many First Nations communities do have access to computers or the Internet. A barrier to effectively using some older computers comes from a general fear of technology. Many CHRs do not use computers daily and CHRs have never used a computer in their lives. Sometimes, people who fear computers also fear showing others that they do not know how to use them. A lot of people older than 50 are not comfortable with computers and exhibit a fear of making mistakes. However, it is a common myth that only the elderly are affected by fear of technology. The truth is that "technophobia" – or fear of technology - is not influenced by age; usually, "technophobia" is related to a person's life experience and how he or she was introduced to computers in the first place. (11)

Users - and not just older and new users - are right to be mistrustful of technology. Many software products are frightening to new users. Usually, computer systems have messages and errors that are hard to understand. Messages such as "fatal error" or "illegal operation" are scary, especially for older users for whom such terms as "fatal" or "illegal" may have a worrying association. As we move further into a hi-tech direction, attitudes and fears are changing. Right now, there is still much nervousness when it comes to using the computer or Internet. (12)

If people are afraid to use computers, can we expect them to accept a complicated and sensitive data system such as the FNIHIS? This is a challenge that must be dealt with for the FNIHIS to be successfully put in place at the community level. The benefit of the FNIHIS is that it is very user-friendly with protection in place to recover from mistakes. It is designed to be easy to use. All a person needs is adequate training to be able to use the system effectively. Many “fear of technology” issues about the FNIHIS or other computer systems can be solved with funding for training and education about technology. Users also need to feel they have support and somewhere to turn if they make a mistake.

INADEQUATE OR LACK OF TIME FOR TECHNOLOGY TRAINING

“It is the Aboriginal take on catch-22. Aboriginal healthcare workers do not have the training resources or the time, in the face of heavy workloads, to access the training that will enable more efficient use of time in the workplace. Their unfamiliarity with and fear of new information technology is an effective barrier that impedes them from attaining basic computer skills that would enhance understanding and comfort levels with this technology.”(13)

Rural and isolated communities must be able to take part in national and world health decisions. One way of making sure that happens is through access to modern information and computers. Computers will also help overcome distance barriers because they can send e-mail and access the Internet. However, people need training in order to use new technology properly. To be useful to a lot of people, modern technology such as the FNIHIS must help different people in different health roles. Rural and more isolated groups of people in Nunavut and Northwest Territories say that it is very difficult to find information on the Internet. This is because the amount of information available keeps getting larger. Technology training is very important to using the huge possibilities of the Internet. (14)

OWNERSHIP AND PRIVACY OF DATA

Aboriginal communities have a historical and legal right to self-government. In the case of the FNIHIS, this would mean ownership of the data contained in it. The AFN believes that control over and health data is essential for Aboriginal communities. (16)

The FNIHIS has many benefits to communities. One benefit is having all of the community data stored in one place. For First Nations people there are many concerns about the privacy and security of their data. Privacy is the right of individuals to decide when and how much information they want to share about themselves and others. Aboriginal Canadians are concerned about loss of privacy. They have concerns about their information being available inside computers.

Some of the privacy issues relating to FNIHIS are as follows:

What information should be included in the FNIHIS?

Who should have access to data in the FNIHIS?

Under what circumstances should the FNIHIS data be shared with other healthcare providers?

How will a patient be able to access his or her own information in the FNIHIS?

In what way can the information in the FNIHIS be used for secondary purposes (e.g. research, administration)? When is the patient’s consent required?

Health Canada believes that protecting health information from bad usage is very important: "Health data must be created, used, transmitted, aggregated, and abstracted in ways and in environments that maintain data security and accuracy, prevent inadvertent or accidental release, prevent or deter access by unauthorized users, and discourage, detect, and punish inappropriate use of health data by unauthorized users." (17). Most provinces and territories are attempting to address health information privacy issues. A few provinces have introduced health privacy laws. The federal government has recently adopted the Personal Information Protection and Electronic Documents Act (formerly known as Bill C-6). This Act will impact the privacy of Canadians in the next few years. The Act applies to the collection, use and disclosure of personal information by organizations during commercial activities. Personal information is any information about an identifiable individual whether recorded or not. Organizations include associations, partnerships, persons and trade unions. "Bricks-and-mortar" and e-commerce businesses are covered by the Act. The term "commercial activity" includes the selling, bartering or leasing of donor, membership or other fund-raising lists. (18)

But the Privacy Act will not affect health data for another year, as it will only on January 1, 2002 be included under the Privacy Act. It is still unclear what organizations will be affected when it does. Many health organizations will argue that their use of health data does not make them any money. They feel that because the health data is not bought or sold, it should not fall under the Act. Critics of the Privacy Act feel it is too weak and will not stop clever organizations from finding ways around it. These organizations will say that the data they collect and share cannot identify individuals. People who specialize in privacy issues do not believe claims that health data will be kept private and nameless. Health information is valuable because it can be linked to certain groups or individuals. If you truly make collection of data anonymous, its value is dramatically decreased (19). These issues are crucial as there are many examples of the misuse of health data collected from aboriginal people across the country. To successfully implement the FNIHIS, the Ownership, Control, Access and Possession (OCAP) of First Nations health data must be appropriately addressed. According to Larry Sault, Grand Chief, Association of Iroquois and Allied Indians, the FNIHIS will not evolve to its fullest potential unless the issue of OCAP is resolved with First Nations (20).

MISTRUST OF AGENCIES AND GOVERNMENT MISUSING HEALTH DATA

"Research on Aboriginal health problems and their interpretation by external agencies such as universities, government departments and the media have caused growing concern during the past few decades. For this reason, any attempt to develop health information systems without the full participation of Aboriginal communities will fail." (24).

What follows is a story about the Nuu-chah-nulth of Vancouver Island, but the exploitation of health data happens all too often to Aboriginal people in Canada:

Genetic researcher uses Nuu-chah-nulth blood for unapproved studies in Genetic Anthropology.

"When it comes to First Nations, they have no codes of conduct. They don't respect us. They take advantage of us," said Cosmos. "It bothers me when our people are used like this. He didn't tell us the whole story. We didn't authorize him to use the blood for anything other than try to find a cure for arthritis, and if he's not using it for the purposes he took our blood for, it should be either destroyed or returned to us."

“He just used us. That’s how I feel now,” said Arlene Paul.

“His research could have helped our people to live longer, happier lives, and for him to hold that information and not tell us anything is just really, really wrong.”

[The genetic researcher, Richard Ward,] argues that what he did was neither wrong nor unethical, as he claims his anthropological work connects with rheumatic research in that it all comes back to those tiny strands of DNA. Whether you’re looking for genetic markers showing a predisposition towards rheumatic diseases, or a gene tracing the history of a people, Ward says the many things revealed through genetic research are all related and inextricable. Back at U.B.C, Ward’s former supervisor Rick Spratley is unhappy with what has happened to the Nuuchahnulth blood, saying what has transpired is problematic for both him and his department, adding, “I would be happy to have a dialogue with the Nuuchahnulth”. “What’s so damaging about a study like this is that it erodes the trust between communities and researchers. Without that trust we’re not going to be able to do a whole lot of important work. That trust is too important to be harmed by any particular researcher, and clearly we need to rectify that.” (25)

Trust is a key factor related to health care decision-making. Some Aboriginal people express doubt and mistrust about every part of the health care system. There is a strong sense that the health-related decisions affecting Aboriginal Canadians are not influenced by Aboriginal people. Politicians often make health decisions. Lacking in population numbers, Aboriginal communities feel largely ignored. Sometimes, Aboriginal people are given health programs that are not appropriate to their needs. According to the National Forum on Health: Report on Dialogue with Canadians, participants felt that health needs should be determined at home, by the community:

“[We] must do what the community wants; community knows what its priorities are.” (Regina)

“[We] need the services to be decentralized and totally determined by the community.” (Quatsino/Coal Harbour) (26)

The FNIHIS must be operated and controlled at the community level. Aboriginal people need to feel confident that their sensitive health data is not exploited. They want to feel that their unique community needs are being met. Without that assurance, the FNIHIS may not be used to its full potential.

LACK OF LEADERSHIP FOR IMPLEMENTING FNIHIS

Strong leadership will be necessary for the FNIHIS to reach communities across Canada. That leadership will involve funding. First Nations’ community leaders need to learn about the FNIHIS and what it can do for their community. Many leaders in Aboriginal communities remain doubtful about computer technology in general. Community leaders are the key to successfully implement the FNIHIS. The community members look to their leaders for guidance when it comes to decisions impacting their health and wellness. If leaders accept the FNIHIS, community members are more likely to see how it can improve their lives.

Activities have begun to help communities start using the FNIHIS. For communities that have the system, Health Canada has provided funding to employ a data-entry clerk. The clerk will enter community health data into the system. Leadership must establish a shared vision and a shared commitment to the FNIHIS for it to succeed. When control of the FNIHIS passes from Health Canada, to First Nations, strong community commitment will make it a much easier process.

Some people have doubts about the FNIHIS. Most of the concerns regard the ownership and privacy of health data and the level of involvement from Health Canada. First Nations communities want their own data to be controlled by their own people. Currently, a process is underway to transfer the FNIHIS to First Nations. At this time, Health Canada still has overall authority over the system. For the transition process to be successful, First Nations communities need to learn all about the system. As community ability increases, the system can move away from Health Canada and into First Nations' control.

In January 2000, the transfer process to First Nations control began with the presentation of a Transitional Plan to the FNIHIS National Steering Committee and **its vision is:**

“First Nations will assume increased authority, control and responsibility over research and data gathering systems to support First Nations self government and to build a distinct, autonomous information structure that will be strategically interconnected to the Canada Health Infoway.”

The transfer process has received approval from the Assembly of First Nations Chiefs Committee on Health and the FNIHIS Executive Committee. A Working Group has been created to oversee the entire transfer process. In January 2001, the Transfer Process was presented to the National Steering Committee.

FNIHIS IS EXPENSIVE AND ITS BENEFITS UNCLEAR. INTEGRATING FNIHIS INTO CURRENT PROCEDURES IS A COMPLEX PROCESS.

The implementation of the FNIHIS will require cooperation. Government and community leaders in First Nations must work together to implement the system. The need for cooperation leaves many discouraged because they think that it will be far too difficult to get the two groups to agree.

The costs of setting up and maintaining the FNIHIS are high and some community leaders do not see the benefits of a system with such a high price tag. Some thoughts about the FNIHIS:

Why switch what we are doing on paper for such an expensive computerized system?

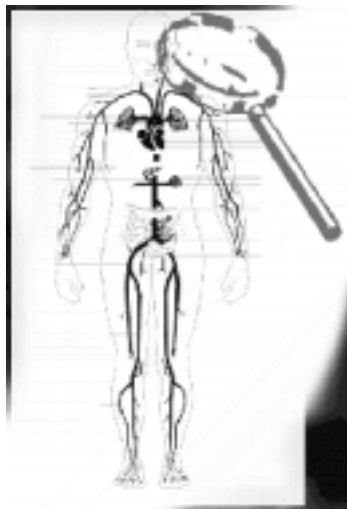
Why spend the time and build the resources when we still do not own the FNIHIS or its data?

Why should we trust that our health data would not be misused as it has so often before?

How do we maintain the human resources we need to run such a system in our communities?

The complications of the system will be addressed more completely when the transition of the FNIHIS to First Nations communities has been completed. There remain weaknesses and barriers with a technology system such as the FNIHIS. As a first step, communities need access to computers and technology. Communities require readily available and reliable access to the Internet. The success of the FNIHIS depends on the availability and use of technology. Some of the more isolated and rural communities struggle with basic telephone line access. This can make connecting to the Internet extremely expensive. Computer use on the job needs to increase, but more training will allow CHRs to feel comfortable using the FNIHIS. When health workers and CHRs use a new technology containing sensitive health data, they may fear making mistakes. Many CHRs have rarely, if ever, used computers in their careers. They need to be given time for training in their work schedule to gain valuable experience with current technology systems.

The ownership and privacy of health data remains an issue for First Nations people. There have been many documented cases of the misuse of First Nations health information. Issues of Ownership, Control Access and Possession (OCAP) with health data will remain until the FNIHIS transition process is complete.



Understanding Community Needs -FNIHIS Focus Groups

by Heidi J. Kuran

The National Indian and Inuit Community Health Representatives Organization (NIICHO) conducted four focus groups across Canada throughout February and March 2001. The First Nations and Inuit Health Information System (FNIHIS) focus groups were held in Vancouver, Regina, Nippissing and Halifax. The focus groups gathered between 8 to 12 CHRs from communities near the four areas selected. The sites selected represented an Eastern, Western, Central and Northern perspective. With all the participants from different places, each person had interesting comments about the FNIHIS.

The FNIHIS focus groups were designed to see how CHRs would use a community-based technology system. There were two reasons for doing the focus groups. First, to determine if the FNIHIS is currently used by CHRs, and second, to identify what barriers may exist if the system is not being used. The focus groups were not intended as problem-solving or decision-making sessions. They were designed to allow NIICHO to encourage group discussion. The four groups were valuable to gain firsthand insight into the CHRs' attitude and understanding about the FNIHIS.

WHAT IS THE FNIHIS?

The First Nations and Inuit Health Information System (FNIHIS) is a community-based computer system that gathers First Nations health data. It is designed as a computer program that is easy to learn. It will provide CHRs and other healthcare professionals with a valuable tool for accessing client health data. It also has an online component so that health data can be accessed through connections to an Internet website. The site is made secure by something called a firewall.

Nobody can get in and see any data without proper authorization.

The FNIHIS contains 12 systems called subsystems. These subsystems can collect health information such as basic client information like names, addresses and phone numbers. It can also collect information about immunizations, reportable diseases and chronic diseases. The subsystems create a set of health facts. These facts will help develop ways to improve health in First Nations communities across Canada. It is also a valuable tool to help track illness and disease trends specific to First Nations and Inuit communities.

The FNIHIS was developed in 1988. Until then, there was no way to pool health data in one place. The Ontario Region's health data was studied and it showed that the way health data was collected was not uniform across the province. It was decided that a Health Information System (HIS) computer program should be developed. The system would create a common way to collect health data was amongst First Nations people living on reserve. Medical Services Branch then created a partnership with First Nations living on reserve and developed the FNIHIS for First Nations communities across Canada.

The system saves CHRs and nurses a lot of time because health files are all in one place. The FNIHIS can keep computerized records on such things as client core information, tests and exams, immunization, medication, reportable diseases, medical allergies, environmental health, public health information, and psychosocial and substance abuse. The immunization subsystem is the most widely used section in the FNIHIS.

The information contained in the FNIHIS is a valuable resource for setting health policies. The data can help communities develop health plans that will suit them. Personal data on the system remains strictly protected and only those people who have an appropriate password can access certain medical records.

The Health Information System was established in order to achieve the following objectives:

Eliminate duplication, reduce the number of forms;

Reduce manual tasks of recording and extracting information;

Standardize health information collection and recording practices;

Increase the reliability of health information;

Improve the flexibility and storage of health information;

Reduce the amount of time required to complete reports;

Improve program planning and evaluation capabilities at the community, zone and regional levels;

Facilitate a proactive rather than a reactive approach to the management of community health issues;

Empower First Nations communities to establish program priorities, which is particularly relevant for the transfer of health services to First Nations control. (27)

According to the First Nations and Inuit Health Programs' 1999-2000 Annual Review in August 2000, the goals of Health Canada and the FNIHIS are as follows:

"In 1999-2000, the First Nations and Inuit Health Programs (FNIHP) Directorate continued to distribute the FNIHIS to First Nations and Inuit communities across the country, and to maintain the existing info- and infrastructures. As of May 30, 2000, the FNIHIS was available in 271 health facilities serving over 330 First Nations and Inuit communities. Distribution of the FNIHIS should be completed in 2000/2001.

2000-2001 Main Activities and Anticipated Outcomes:

Migrate from one national, to multiple regional network infrastructures.

Complete the distribution to communities.

Study the feasibility, design, pilot and implement links to other MSB systems.

Study the feasibility, design, pilot and implement links to provincial systems.

Maintain the FNIHIS info/infrastructures on an ongoing basis." (28)

Each focus group began with an opening session outlining the purpose of the FNIHIS focus group project. Immediately after, a local representative from Health Canada's First Nations and Inuit Health Programs (FNIHP) demonstrated the FNIHIS and explained Health Canada's role in the FNIHIS, what its plans are for implementation of the system, and outlined the benefits of the FNIHIS to First Nations Communities. Because each FNIHP presenter was different for each focus group, uniformity among the groups could not be guaranteed as each representative may have highlighted slightly different aspects of the FNIHIS. However, the four focus groups were asked the exact same questions in the same order after the demonstration.

The focus groups involved systematic individual commentary by each member present. The compilation of ideas was recorded on tape and also typed up by a recorder present at each session. The focus group allowed for ideas, concerns, issues and recommendations to be explained fully and clearly. The ideas and topics presented were surprisingly similar and consistent throughout all four focus group conferences. In assessing the needs identified by all participants, there was a great deal of common ground throughout the different areas of Canada.

The four focus groups were asked the following questions:

I. General - CHR's' Role with Health Data in the Community

As a CHR, do you collect health data in your community? How?

II. Technology Use in the Community / Barriers to Using the FNIHIS

Does your community use modern information technology (computers, the Internet, database collection systems)?

Does your community have any/adequate access to modern technology and the Internet?

Was this the first time you have seen how the system works?
Have you used the FNIHIS in your community?

Do your community leaders and healthcare workers support the use of the FNIHIS?

III. Training for Technology and the FNIHIS

Have you had training on how to use tools of information technology?
(ie: basic computing or Internet training)

Would your current workload allow you the time to take such courses?

How should training be conducted for the FNIHIS system?
What do you think would be most effective training for your community?
(eg. Group Education, Web Training, Self-Learning Packages, One on One Training, On-Site Community Training, Off-Site Training)

IV. Confidentiality of First Nations Health Data

Do you have any concerns regarding the types of data in the FNIHIS?

Do you think that the privacy of First Nations health data has been adequately addressed by the FNIHIS?

Is any health data too sensitive to store in the FNIHIS?

V. FNIHIS Role in First Nations Health

Do you think that the benefits of the system to the community/CHR are worth the costs/time?

How could the FNIHIS be improved?

FOCUS GROUP OBSERVATIONS

The focus groups covered four distinct regions of Canada and therefore presented unique experiences for the focus group facilitators at each location.

Vancouver, British Columbia

At the Vancouver focus group, most of the participants had some exposure to the FNIHIS and were eager to see the demonstration to understand how the system could be used in their communities. One of the focus group participants was a data entry clerk who will be entering data for as many as 18 bands.

After the introductory information provided by the facilitators, the participants were interested in the system based on what they understood about it. The demonstration of the FNIHIS was tailored to the ways in which CHRs could use the data collected in the system. This was vital to the participants learning more about the FNIHIS. After the demonstration, the focus group could see many ways in which the FNIHIS could benefit their healthcare processes. They particularly liked the immunization and public health subsystems that would be extremely valuable to CHRs. One CHR in the group gathers data on diabetics in her community and felt that the chronic disease subsystem would be extremely valuable in her community.

The focus group facilitators were pleased to note the level of interest and willingness of the participants to accept the FNIHIS in their communities. Several participants represented communities that already had the system and were entering data. One community had a data entry clerk in place to begin gathering data. Other communities were getting the system very soon. Most communities represented in the focus group seemed well organized to take on the FNIHIS.

Most participants agreed that in order to use the FNIHIS effectively, they would require training. The participants said that leaders in their communities held training as a high priority but finding the time in their busy schedules was an issue. Most mentioned that they required better access to computers and the Internet so that they could practice what they learn.

Regina, Saskatchewan

Many participants in the Regina focus group had little exposure to the FNIHIS. However, the group was very interested and willing to learn about the system. During the introduction the facilitators discovered that there were two participants in the group were actually working directly with the system and entering data. There was a definite sense that this was an overwhelming task in addition to their other duties. A data entry clerk was a valuable resource to those who mentioned entering data themselves. The two who were entering data did not have all data in the system so they did not feel that it was producing effective results for their communities yet. They predicted that when all data will be present, they will use the system to generate reports to help them better plan health initiatives in their communities.

After the demonstration of the FNIHIS, the participants had many questions about data privacy and security. The members of this group were very concerned about who would have access to data and how that data would be used. An explanation of the security model in place helped the group understand the protection that the FNIHIS has built into the system. The Regina focus group seemed willing to accept the system as long as there were stringent data confidentiality measures in place. The biggest issue at this focus group was whether or not the data would be used outside the community and at the regional and national levels. It was explained to the group that all data used would be for each particular community with complete authority at the community level.

Again, barriers to using technology and the FNIHIS were lack of training and lack of ready access to computers. All participants saw the value of using computers in their daily tasks, but most did not have computers at work. In one case, there is only one computer for an entire office and many have to share it.

Nippissing, Ontario

The Nippissing focus group was alive with enthusiasm about the FNIHIS. After the demonstration, the participants saw the potential timesaving aspects of the FNIHIS that would help them immensely in their daily tasks. Several interesting ideas came up during this focus group. One unique perspective was that knowledge should be shared among users to create a help network. In Ontario, the Health Canada representative for FNIHIS advocates users helping users and often puts new users in touch with those who are more experienced. Those actually entering the data have an intimate knowledge of the system and can share their knowledge and act as teachers for those new to the system.

Once again, poor access to technology was mentioned as a barrier to using the FNIHIS. Participants mentioned having one computer for an entire clinic. They also talked about needing training not only in technology but also in medical terminology so that they can understand the meaning of the data they enter into the system.

Participants indicated that the communities which show the most interest in the system have leaders who advocate its use and have helped convince their people of its value.

Halifax, Nova Scotia

The participants at the Halifax focus group had little or no experience with the FNIHIS. One person had seen the system years earlier but not since. Like Regina, this group was concerned about privacy issues and data ownership. One person in the group expressed distrust about having her own data in the system. She mentioned that she would not want to be included in the system herself and risk having another CHR or colleague access her health history.

Most participants felt that they did not have enough training to feel confident with technology – especially entering confidential health data. Participants mentioned that training programs were hard to attend due to workload. It was also mentioned that training was not a priority in some communities. Again, participants in Halifax mentioned that computers were hard to come by and in one case locked up to limit access. It was noted that the participants did not routinely use computers or the Internet at work. It was also noted that community leadership for technology might be lacking because Health Directors were not advocating using technology or the FNIHIS at the community level.

CONCLUSION


The focus groups' comments indicate that access to computers and the Internet remains a barrier for using systems like the FNIHIS. Using computers is still new to many CHRs to use computers and most do not have ready, individual access to the Internet. According to several focus group members, entering data into the system themselves would be too labor-intensive. This task would take CHRs away from their duties as caregivers. Without funding assurance from Health Canada for a data-entry clerk, many focus group participants remain doubtful about the FNIHIS.

Effective FNIHIS training is important for CHRs to feel comfortable using the system. The focus groups all mentioned training as a barrier to using computer technology. CHRs want to be trained for technology but many experienced CHRs are older and have had little or no exposure to computers or the Internet.

The focus group responses support the need for additional technology training among CHR's and other health professionals. To contribute to technology education in First Nations and Inuit communities, training must focus on building skills in technology. It must also address the need to understand data privacy issues.

The FNIHIS is in the process of transition from government to First Nations' community control. In the next several years, the barriers to using the FNIHIS will not be about technology but more about ownership, control and access to data. First Nations and Inuit need community-based health management skills and training to manage their own health data requirements. No data exists that finds one style of training more effective than another so First Nations have an excellent opportunity to determine how they would like to learn.

Information gathered from the focus groups indicates that although the FNIHIS handles many health data collection needs, many more can be addressed with improvements in future releases of the system. First Nations must be involved in the process of determining additional features relevant to their needs. For CHR's to feel comfortable using the FNIHIS, they must have a system that fulfills their requirements.



Using the System: Who is Entering Data into the FNIHIS?

by Heidi J Kuran

Some of the participants at the NIICHO FNIHIS Focus Groups had seen the FNIHIS but had never entered data into it. Many communities are successfully entering their data into the system. Tara Backman of the Sto:lo Nation in British Columbia has the task of entering data for 18 bands. Tara was hired as a data entry clerk in her community. She has been entering data since April 1st, 2001. Tara is the sole user of the system right now as she adds more and more of her community's information into the FNIHIS.

Tara has entered approximately 30 of her community's health files so far. Her user id and password give her access to all of the subsystems in the FNIHIS. Tara has put Client Core and Immunization data into the system. It is a labour-intensive process but she has a good start on the big job ahead of her. Tara feels that the system is very user-friendly and she can enter information very easily.


As with any new system, there are challenges to face. These challenges will be addressed in the future of the FNIHIS. Tara raised issues about the things that make it hard for her to enter data effectively. She relies on Internet access to enter the records and sometimes, technical difficulties prevent her from getting on to the Internet to complete her task.

Other challenges are not so much technical, but occur when entering the data. When Tara uses the Immunization subsystem, it is sometimes hard for her to understand the medical terms to accurately enter which shots should be recorded. She has access to only one nurse to discuss this with. That nurse is very busy and it is hard to sit down with her to discuss problems. Sometimes Tara enters data from old, hand-written reports and charts that are difficult to read. Different handwriting is often hard to understand especially if it is not neat. Tara feels that a nurse educator will be a welcome addition to the training team for the FNIHIS. A nurse educator will have many of the non-technical answers.

In terms of FNIHIS training, Tara has had a two-day training program. The training was held in Richmond, BC. Tara felt it was a bit short and would have appreciated more training on entering data. She would also have liked training to understand the meaning of some of the health terms used in the system. If Tara has technical questions she has support people to call using a 1-800 number. However, help does not come quickly. Her questions are often answered in time, by her own trial and error.

Overall, Tara likes the system a lot and can see that it will be very helpful for creating reports. She thinks she can use the data in the system rather than having to go through all of the individual paper health files. She admits that several people in her community have questions about the FNIHIS. Their questions concern whether the data in the system will remain private and safe. Tara feels that once people understand the levels of security in the FNIHIS, they will feel more comfortable with storing data in it. From Tara's point of view, she feels that FNIHIS security is good. She understands that there are different levels of access to the system according to user ids and passwords. She feels confident that the firewalls and other security measures will keep the information private.

With further training, experience and support, Tara thinks that the FNIHIS will be a valuable tool for her community and for CHR's in planning their activities. Eventually, once the data is in the system, CHR's will be more involved with the FNIHIS. Tara hopes to have all records in the system by February 2002.



Into First Nations Hands: The Transition Process of the FNIHIS

by Heidi J. Kuran

“The FNIHIS will never be what it was intended unless the issues of OCAP (Ownership, Control, Access, Possession) are addressed.” – Jane Gray

Jane Gray is the National First Nations and Inuit Health Information System Coordinator for the Assembly of First Nations. Jane works with First Nations and Health Canada to ensure that there will be an effective transition of the FNIHIS into First Nations' hands. In addition, Jane also holds a position on the First Nations Information Governance Committee (FNIGC). This group governs the transition process and will work towards moving the FNIHIS to First Nations. Currently, the FNIGC is developing a transition implementation plan. The plan will clearly describe how the process will be handled.

The FNIGC's vision is:

“First Nations will assume authority, control and responsibility of research and data gathering systems to support First Nations self-government and to build a distinct, autonomous infrastructure that will be strategically interconnected to the Canada Health Infoway.”

To effectively transfer control of the FNIHIS to First Nations, the FNIGC has many responsibilities. The Transition Process Plan will:

SEEK FINAL MANDATE FROM FIRST NATIONS LEADERSHIP FOR GOVERNANCE COMMITTEE AND FNIHIS.

SEEK MEDICAL SERVICES BRANCH SUPPORT BASED ON THE PARTNERSHIP PROCESS.

SEEK FUNDING TO HIRE A FIRST NATIONS HIS NATIONAL COORDINATOR.

REDESIGN & REALIGN THE STRUCTURE OF THE PRESENT FNIHIS NATIONAL STEERING COMMITTEE.

STRENGTHEN, ADVANCE & INTEGRATE THE FNIHIS RESPONSIBILITIES FOR HUMAN CAPACITY DEVELOPMENT AND TRAINING AT ALL LEVELS.

ESTABLISH THE APPROPRIATE PARAMETERS AND GUIDANCE FOR THE CONTINUED TECHNICAL CAPACITY IN DEPLOYMENT, MAINTENANCE, SYSTEM INTEGRITY, AND SUSTAINABILITY OF FNIHIS WITHIN THE TRANSITION OF RESOURCES.

SUPPORT FIRST NATIONS CONNECTEDNESS BETWEEN REGIONS VIA THE NATIONAL SERVERS WHICH WILL BE GOVERNED WITHIN A FIRST NATION MANDATED INSTITUTE.

IMPLEMENT A JOINT COMMUNICATION STRATEGY ON THE FIRST NATIONS INFORMATION GOVERNANCE COMMITTEE WITH REGARD TO THE FNIHIS INITIATIVE.

ENCOURAGE AND STIMULATE THE ECONOMIC DEVELOPMENT AND CAPACITY OF FIRST NATION COMMUNITIES, ORGANIZATIONS AND BUSINESSES BY UTILIZING & SUPPORTING THE ABORIGINAL PROCUREMENT POLICY.

According to Jane Gray, statistics for FNIHIS implementation are encouraging. Out of a total of 580 sites, 349 are in operation already. That represents a 60% implementation rate. However, she admits there are some issues preventing the FNIHIS from gaining greater acceptance. These issues involve OCAP (Ownership, Control, Access, and Possession). Issues of privacy are paramount. Users will need assurances that their data will be controlled at the community level. The government or other agencies must not misuse it. A privacy impact assessment is in the process right now to help gauge First Nations needs. The assessment will ensure that data will not be shared, sold or otherwise misused. Health Canada has put together a Privacy Working Group to try to find solutions to health data privacy issues. Resolving these issues is vital to the success of the FNIHIS.

In addition to barriers of OCAP, further training is necessary for users to feel confident entering sensitive data. Ms. Gray feels that FNIHIS training will need to focus not only on technical skills, but also on managing health and epidemiological data. In the near future, Health Canada will focus on hiring a nurse educator to take on the education portion of the FNIHIS implementation.

According to the FNIGC, the transition process will mean that the FNIHIS will:

Be managed under the direction of the First Nations Information Governance Committee

Support First Nations community-based Ownership, Control and Access (OCA) of data collected and integrated within the regional and national FNIHIS structure.

Support governance capacity at the community, regional & national levels by including the provision of technical support and resources for effective, sustained development and management.

Be strategically interconnected to the broader Canadian Health Infostructure under First Nations governance.

Provide, among other initiatives, a strategic, supportive and sustained infrastructure tool that will assist in improving First Nations health status.

Advance the development of an integrated stewardship model that respects the integrity and protection First Nations individuals and communities.

Provide credible, relevant information within a mandated community, regional and national process that is approved by all stakeholders.

Once the transition process is finalized and ready to be implemented, Jane Gray feels that First Nations will be more inclined to use the FNIHIS. One of her mandates is to communicate with users of the system. System users include data entry clerks and nurses, the National Deployment Team, and the National Steering Committee. Jane attempts to understand the issues arising for each group involved with the system. Those who work most intimately with the system are in the best position to provide feedback on its strengths and weaknesses. They can offer valuable suggestions for its improvement.

Currently, the FNIHIS application is at Version 2. The improvements over Version 1 are considerable. There is a much better look and feel to the system. This translates into improved usability. The improvements were made possible by user group input. Another significant advance with Version 2 is the involvement of the Internet. FNIHIS Version 2 has a Web-based portion so users can enter data through an Internet connection. This means that they do not have to have the whole application on their desktop computer where it can take up a lot of space.

Individual communities have the job of entering their data into the system. Data entry can be a burden to already overworked nurses and CHR's. To help out, Health Canada has provided communities that have the FNIHIS with yearly funding for a data entry clerk. At this point, the data entry clerks and nurses are the primary users of the system. Once the data has been entered, CHR's will have a more active role using many of the systems within the FNIHIS to plan their community health activities.

Eventually, the FNIGC's goal is to establish the FNIHIS and other First Nations data and technology systems as wholly owned and controlled by First Nations. The FNIHIS will only be an effective tool for First Nations once they are in control of their own data and processes for collecting and storing that data. First Nations must own the system and all decisions regarding it. Only when First Nations become the primary users and owners of the system will trust emerge.



HIGH TECH CHR's:

The Future of Community Health in First Nations



First Nations reserve communities and many towns are spread throughout mountainous terrain. These areas have difficult weather and poor road conditions. Some communities are still only accessible by air or water. Some areas have very few doctors and nurses. First Nations communities rely on Community Health Representatives (CHRs) for much of their day-to-day care. CHRs are primarily women and some have limited formal education. CHRs gain their training and experience through a variety of ways. For example, CHRs attend with and learn from older women who may be traditional healers or midwives. CHRs get on-site training by “fly-in” nurses, from doctors, or through off-site certificate or non-certificate training on specific topics.

When training occurs outside of their community, CHRs may not have the same opportunity to control how they learn. CHRs have a wide range of educational levels, learning styles, cultural understandings and experiences. Education must not be too fast-paced and complicated. Most CHRs appreciate hands-on, visual learning and support so they can ask questions. Colleges and universities do not recognize many CHR training courses. This means that there is little opportunity for educational advancement for CHRs interested in pursuing a medical career.



The Internet now provides a lot of health data. With training, a CHR has the ability to effectively access information that she can bring back to the people in her community. For a system like the First Nations and Inuit Health Information System (FNIHIS) to be a useful tool for CHRs, training must be provided that is specific to them and their role.

The Portage College in Lac La Biche, Alberta has a program that helps CHRs learn about computers and technology. Their pilot program called Community Health Representatives On-Line helps CHRs maintain and upgrade their technology skills. This is a big challenge for CHRs in remote or isolated communities. The primary goal of this program is to “increase the effectiveness of individual CHRs.” The program helps raise the standing and authority of CHRs as health professionals. The nursing shortage in Canada means that nurses are continually too busy and overworked. As a result, CHRs continue to take on more healthcare issues. CHRs act as health information agents in their communities and play a major role as educators. They promote good health and help prevent injury and disease. CHRs affect the greatest change in their communities when it comes to healthcare. As Aboriginal people themselves, CHRs help bridge any cultural gaps between healthcare professionals and their communities.

The Community Health Representatives On-Line program uses information and communication technologies to help CHRs talk to each other. The pilot of this project was very successful and encompassed 30 different pilot sites in Alberta. As a result, 53 frontline CHRs, with little or no previous computer experience, learned basic computing and Internet skills. Most of the 53 CHRs who took the program can now surf the Internet. They can now find reliable and culturally appropriate health data. They can also communicate with their colleagues in other communities by e-mail.

All of these advancements have helped CHRs gain standing in their community. Graduates of the program prove to their community that they are healthcare workers willing to use all the tools available to them – including technology – to help their community.

The basic CHR training course has evolved over time. Some CHRs who took their training years ago have not had a chance to upgrade their skills. The instructors for CHRs On-Line are experienced with users that have little or no computer experience. They have developed the CHRs On-Line program with that in mind. To begin with, CHRs are taught basic computing to get comfortable with technology.

Those with some computer experience are provided with a refresher to get them back up to speed. The new computer skills gained in the CHRs On-Line program are valuable and can be brought back to their communities and taught to others. More importantly, CHRs are able to show their leaders why technology is important to their jobs and how it can help them. Furthermore, CHRs do not have to travel long distances to get training because education happens on-line through the Internet.

CHR can learn from home or from their office. The CHRs On-Line program has gained national attention. Many communities across Canada including the Northwest Territories and Nunavut have inquired as to how they can get involved. Here are some comments from CHRs who have participated in the program: "I believe it is a great project. Once we CHRs are connected, it will be great. I sure hope everyone will have connection with a computer, so that the distance will be a thing of the past. (We) can connect by a push of a key and (are) able to share information. This is the future for native CHRs." Rachel Ermineskine, Southern Alberta CHR Advisor, Siksika.

"I find it very helpful to be connected online. Just reading someone else's comments helps me realize that there are other CHRs working out there. I know it could be useful when I need the latest information or information that our resources lack". Lorraine Cardinal, CHR, Saddle Lake, Alberta.

Overall, survey comments received from CHRs who participated in CHRs On-Line were very positive. The program is especially helpful in situations where there are lone CHRs in isolated communities. Approximately 38% of those surveyed now use the CHR On-Line website. A full 20% use the site at least weekly. Many of the CHRs On-Line students now have computers at work after their employers realized their value to CHRs. These CHRs will have no trouble transitioning to operate the FNIHIS because they will have the basic skills they need to use and feel comfortable with the system. (15)

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ABOUT THE NATIONAL ABORIGINAL HEALTH ORGANIZATION (NAHO)

The newly designed NAHO is an Aboriginal-controlled, non-profit corporation committed to improving the physical, social, mental, emotional, and spiritual health and well-being of Aboriginal peoples. NAHO is mandated to create, analyze, and undertake research that will promote and improve the health of Aboriginal peoples.

The five national member organizations are:

- the Assembly of First Nations;
- the Congress of Aboriginal Peoples;
- Inuit Tapirisat of Canada;
- the Métis National Council; and
- the Native Women's Association of Canada

The Objectives of the Organization are:

To improve and promote, through knowledge-based activities, the health of Aboriginal peoples and Aboriginal communities including women, children and youth, the elderly, and urban Aboriginal persons.

To promote understanding of health issues affecting Aboriginal peoples including women, children and youth, the elderly, and urban persons by means that include communities and educational activities.

To facilitate and promote research and develop research partnerships relating to Aboriginal health issues, including research relevant to women, children and youth, the elderly, and urban Aboriginal people.

To foster recruitment, retention, training and utilization of Aboriginal people in the delivery of health care.

To affirm traditional Aboriginal healing practices through validating traditional holistic practices and medicines and ensuring such practices are recognized.

The newly appointed Executive Director is Richard Jock.

**For more information, visit their website at www.naho.ca
or contact 56 Sparks Street, Suite 400, Ottawa ON K1P 5A9,
Toll free - 877-602-4445**

A SIMPLE VIDEO FINDS SUCCESS AGAINST SHAKEN BABY ABUSE

By Lisa W. Foderaro (taken from New York Times)



Buffalo, May 29, 2001 - The education of new mothers at the Children's Hospital of Buffalo has long included instruction in breast-feeding and the importance of using car seats. But these days, during the tender, joyful hours after a baby's birth, the orientation in the maternity ward here has an additional, sobering element: a video about one of the most lethal forms of child abuse, violently shaking an infant, along with the request that parents sign an affidavit saying that they understand the risk. These may seem like small measures, lasting no more than 15 minutes. But the early results have been impressive. In the six years before the program began in several counties around Buffalo, there were 6.5 reported cases of forcible shaking per year, on average. In the two years after the program's introduction in late 1998, that average dropped to 1.5, excluding babies born before the program began. Shaken baby syndrome remains a misunderstood, underreported and secretive form of child abuse. Unlike children who arrive in the emergency room bleeding, bruised or with broken limbs, these patients have injuries that are invisible, and thus more easily denied. But recent high-profile cases have increased public awareness. Now, a paediatric neurosurgeon at the Children's Hospital of Buffalo, Dr. Mark S. Dias's approach has given health care professionals a new prevention tool, and is fielding inquiries from hospitals from Maryland to Arizona.

Dr. Dias has long treated babies with seizures, paralysis, brain damage, blindness and other grave impairments caused by shaking. One-quarter to one-third of them die. But only after the birth of his son did he feel compelled to prevent these injuries and deaths, not merely react to them. It had become personal. As a new father, he would put his son down to sleep and turn and leave the room, only to be summoned back by the infant's renewed cries. Sometimes, the routine was repeated as the night wore on, leaving him increasingly frazzled and impatient. "It was during that time that I really started to understand how people could feel driven to frustration and rage," He said, "how they could lose control." The program is still young, but its success has caught the attention of child-abuse experts. The video features three parents talking about their injured babies, interspersed with advice from health care providers. It ends with images of the children: one in a wheelchair, another breathing through a tracheotomy tube and the third represented by a tombstone. One new mother commented: "The video was a little depressing – to see that people could do that to a child, but it's a good thing to show people, because they might not be aware of it."

For more information contact the National Center on Shaken Baby Syndrome in Ogden, Utah:

Tel: (801) 627-3399 or if you have questions regarding this project call Debra Williams at the National Center at (801) 627-3399 or e-mail

dj-williams@mindspring.com.

Email: dontshake@mindspring.com