

## **PART I: INTRODUCTION**

On October 22, 1997 the Minister of Health, Clay Serby, announced a public consultation process on the protection of health information. The principal tools for the consultation were a Consultation Paper and Questionnaire on the Protection of Health Information. Individuals and organizations were asked to consider a range of issues related to protecting health information and to respond with a completed questionnaire or by other means, by November 28, 1997.

Following the Minister's announcement, more than 1200 copies of the consultation package were provided to the public, health providers, district health boards, consumer groups, special interest health groups, researchers, MLAs and the media. The consultation was promoted in a press release; newspaper ads (dailies and weeklies) during the first week of November; and, an interview on Cable Regina.

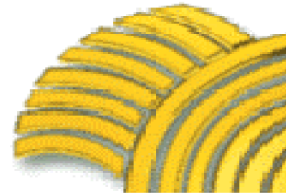
Responses to the consultation have exceeded expectations based on Alberta's and Manitoba's experience with similar processes; 140 were received as of January 7, 1998, most arrived before December 3, 1997. The responses are from a range of individuals and organizations including

- § the public,
- § health providers,
- § organizations of health professionals,
- § consumer groups,
- § district health boards,
- § health research
- § health advocacy groups.

This report summarizes the responses received and analyzed by January 7, 1998. The responses have played a significant part in the review of legislation and in the preparation of preliminary drafts of a proposed bill further protecting personal health information.

*Consultation Paper  
on*

# **Protection of Personal Health Information**



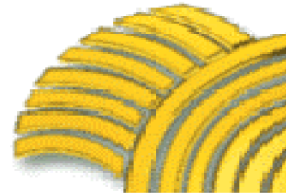
## **RESULTS OF THE CONSULTATION**

The questionnaire was divided into three parts:

- Part I dealt with broad principles and asked preferences for legislative actions (stay with status quo, amend existing legislation or enact new legislation).
- Part II dealt with a number of health information issues which can be addressed in legislation or policy.
- Part III contains a general section which posed additional questions and provided an opportunity for comments

This report follows the pattern of the questionnaire. Each section reports the statistical breakdown of responses and provides examples of written comments. While percentages are shown for each response, it should be noted that some questionnaires may represent the views of organizations while others represent individual opinions. The level of response shows general trends, but should not be interpreted as a statistical sample of opinion. Written comments are presented in no particular order.

All personal identifiers have been removed from quotations. Editing of the quotations has been kept to a minimum.



## **PART I:**

### **LEGISLATIVE OPTIONS**

The responses to the question of preferred legislative action show a very high level of support for new legislation.

- 71.4% of those responding indicated a preference for new legislation aimed specifically at protecting health information. Another 9.3% preferred amendments to existing legislation, while only 2.1% wanted to stay with the status quo. 17.1% offered no opinion.

One respondent working in the health system wrote:

*"This legislation is urgently needed and needs to apply to all sectors of health care."*

Another, offered an opinion of the status quo:

*"The current legislation regarding health information seems inadequate and does not cover the technological advances made since 1979 (Hospital Standards Act)."*

Another, whose preference was for the status quo, offered the following statement of concern with taking legislative action:

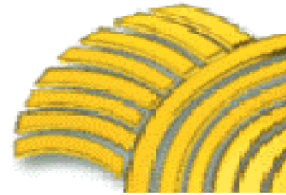
*"Because of the complexities in defining legislation for privacy, such legislation tends to be too restrictive for the good of the individual patient or research purposes."*

### **FINDING A BALANCE BETWEEN PRIVACY AND USE**

Responses to the series of questions in Part I reflect the difficult task in trying to strike a balance between the need to protect the privacy of health information while at the same time ensuring that health information is available when needed in order to provide health services.

On the one hand there was strong support for statements limiting the collection, use and disclosure of personal health information:

- 75.7% of respondents agreed strongly with the statement: "Personal information should be collected only for necessary purposes." (75.7% agreed strongly, 16.4% agreed, 4.3% agreed somewhat, 0.7% disagreed somewhat, 2.9% disagreed strongly and 0% offered no opinion.)



- 82.4% agreed or agreed strongly that: "The privacy of individuals is protected by limiting the use and disclosure of personal information for legitimate health needs and for legally sanctioned purposes, such as criminal investigations." (52.1% agreed strongly, 29.3% agreed, 7.9% agreed somewhat, 3.6% disagreed somewhat, 2.1% disagreed strongly and 5.0% offered no opinion.)

At the same time, respondents were concerned that their health information be available when it is needed to provide services:

- 98.5% indicated agreement with the statement: "It is important that the right people have access to the information at the right time. For example, emergency room staff need access to your health information to make rapid decisions regarding your care." (79.3% agreed strongly, 12.1% agreed, 7.1% agreed somewhat, 0.7% disagreed somewhat, 0.7% disagreed strongly and 0% offered no opinion.)

The written comments help explain some of the concern and the difficulty with finding the balance. Some examples include:

*"'Legitimate health needs' may need to be defined. Posting lists of people infected with blood from pathogens for example is NOT legitimate."*

*"Allergies to medication is important to know in emergencies, but, there is a lot of other information that is not required. Reliance on past history may create an inaccurate treatment for some conditions, this is why people get second opinions."*

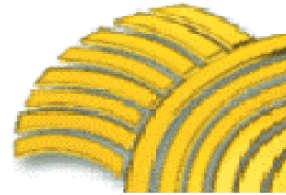
*"Don't hamstring the system by an inordinate amount of restrictions on who and when access is available. Protect the system by ensuring there is strict consequences for violations."*

*"The key is how you define 'legitimate health needs'. Some staff believe they have the right to certain information even if the client doesn't want them to have it."*

## **THE RIGHT TO EXAMINE AND REQUEST CHANGES**

There was also very strong support for individuals having the right to examine and to request corrections to their personal health information:

- 100% indicated agreement that: "Individuals should have a right to examine their personal health information." (75.0% agreed strongly, 20.7% agreed, 4.3% agreed somewhat, 0% disagreed somewhat, 0% disagreed strongly and 0% offered no opinion.)



- 95.6% indicated agreement with the statement: "Individuals should have the right to request corrections to their health information." (61.4% agreed strongly, 22.1% agreed, 12.1% agreed somewhat, 2.1% disagreed somewhat, 0.7% disagreed strongly and 1.4% offered no opinion.)

Yet even support for these rights was sometimes qualified. One respondent wrote:

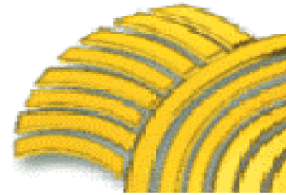
*"The word 'corrections' may need to be changed or defined somehow. I have seen patients view their hospital health records & have taken exception to words such as 'depressed', 'drug/alcohol addict', 'uses street drugs' & have wanted those terms removed from their record."*

Another offered the following advice:

*"Individuals should have more of a right than to simply 'request'; should be able to 'log on the record' their disagreement."*

A health records professional wrote:

*"In some instances, allowing persons to examine their personal health information may need further clarification. For example, many medical reports are very technical in the language used (e.g., OR reports, pathology reports, investigations - CT, MRI, etc.). For 'non-medical' people to interpret this information, it may be very difficult. In our profession (health record management) we often suggest that a person wanting to review their own record should do so in the presence of their physician or other health care provider, so that items may be clarified for them."*



## **PART II: ISSUES**

### **1. TYPES OF HEALTH INFORMATION**

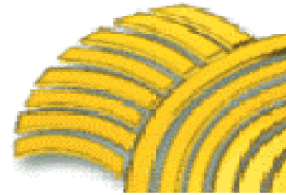
Most respondents agreed strongly that identifiable personal health information should only be available to those who have a need to know. On the other hand, there was very high support for making de-identified individual information available for research, evaluation, monitoring and improving the health system.

- 92.9% indicated agreement with the statement: "Personal health information containing specific information about an individual's health should only be used by those who need to know." (69.3% agreed strongly, 19.3% agreed, 4.3% agreed somewhat, 2.1% disagreed somewhat, 1.4% disagreed strongly and 3.6% offered no opinion.)
- 97.1% had some level of agreement with the statement: "Personal health information may be accessed with the patient's consent, or for purposes consistent with the reasons the information was collected." (50% agreed strongly, 41.4% agreed, 5.7% agreed somewhat, 2.1% disagreed somewhat and 0.7% offered no opinion.)
- 99.3% indicated a level of agreement with the statement: "Unidentifiable individual information may be available for specific well-defined research purposes, to evaluate health services and improve the effectiveness of the health system." (51.4% agreed strongly, 40.7% agreed, 7.1% agreed somewhat, 0.7% disagreed somewhat, 0% disagreed strongly and 0% offered no opinion.)
- 97.1% had agreement with the statement: "Statistical and aggregate information may be widely available for planning, evaluation, reporting and research." (56.4% agreed strongly, 34.3% agreed, 6.4% agreed somewhat, 1.4% disagreed somewhat, 1.4% disagreed strongly and 0% offered no opinion.)

The written comments included the following:

*"Registry information should be available for government and local planning. Personal health information should be available to all health professionals involved in the treatment of a patient. Unidentifiable individual information must be available for research purposes."*

*"...there is a need for others to have access to my 'personal' health information if my condition poses a threat to the health or well being of others. I would not favour legislation or policy limiting their right to access if this were the case."*



## **Sharing of Registry Information**

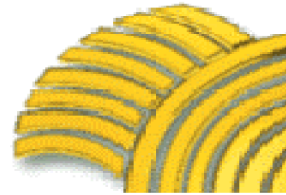
The majority of respondents supported the sharing of registration information between government agencies. However, the support was generally not as strong as for other uses for health information identified in the questionnaire.

The strongest support for sharing registration information was for sharing by the Department of Health to district health boards.

- 93.6% indicated agreement that: "Registry information collected by the Department of Health may be available to district health boards for the provision of services, planning and administration." (41.4% agreed strongly, 44.3% agreed, 7.9% agreed somewhat, 2.9% disagreed somewhat, 2.9% disagreed strongly and 0.7% offered no opinion.)

However, when asked to indicate a level of agreement for the government sharing registry information with other government agencies, the support was less.

- 71.5% indicated agreement with the statement: "Registry information may be shared with other government agencies to help reduce administrative overhead costs." (18.6% agreed strongly, 27.9% agreed, 25.0% agreed somewhat, 14.3% disagreed somewhat, 12.1% disagreed strongly and 2.1% offered no opinion.)
- 67.1% had some level of agreement with the statement: "Registry information may be shared with other government agencies or programs only for provision of health services." (12.9% agreed strongly, 37.9% agreed, 16.4% agreed somewhat, 19.3% disagreed somewhat, 10.0% disagreed strongly and 3.6% offered no opinion.)
- 60.8% indicated agreement with the statement that: "Registry information may be shared with other government agencies or programs for non-health services, only in limited circumstances and for legislated purposes." (17.9% agreed strongly, 25.0% agreed, 17.9% agreed somewhat, 22.1% disagreed somewhat, 14.3% disagreed strongly and 2.9% offered no opinion.)



The concern about sharing information in government is evident in the following response:

*"Registry information may be used for health purposes and in the health district as well as by the people who need to know. The emphasis is on 'NEED' to know...to provide information to 'government agencies' is a license to let everyone know, as there are many different government agencies who may have an interest, but not a need to know."*

While the responses indicated support for sharing limited information within government, it was a cautious support. The responses suggest that sharing should be minimal, for a defined purpose, and should be only among those who need to know.

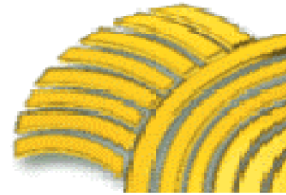
## **2. OWNERSHIP OF RECORDS**

### **Client-Provider Relationship**

Strong preference was shown for maintaining personal health information close to the client-provider relationship.

- 81.4% indicated agreement with the statement: "...responsibility for the record should remain with the doctor, hospital, or whoever is closest to the client/provider relationship, not with a central agency managing data collection." (46.4% agreed strongly, 25.7% agreed, 9.3% agreed somewhat, 7.1% disagreed somewhat, 7.1% disagreed strongly and 4.3% offered no opinion.)
- 32.9% had some level of agreement with the statement: "All health information should be owned and controlled by a central agency responsible to the government." (7.9% agreed strongly, 10.7% agreed and 14.3% agreed somewhat, 26.4% disagreed somewhat, 35.7% disagreed strongly and 5.0% offered no opinion.)
- 95% indicated agreement with the statement: "...the individual has rights to access her or his own information and has some control over what happens to that information." (62.1% agreed strongly, 23.6% agreed, 9.3% agreed somewhat, 1.4% disagreed somewhat, 1.4% disagreed strongly and 2.1% offered no opinion.)





The following written comments are reflective of the concerns:

*"The wording is so restrictive here. 'Ownership', 'control'! Management of, responsibility to, would be easier to respond to."*

*"I prefer that client information remains close to the patient. I probably don't have a lot of confidence in a hi-tech system to be sensitive to each individual's concerns about his/her own case. I could be wrong and am open to new information."*

*"The pt's [patient's] information becomes distant from where actual decisions are made, making access difficult. It gives the opportunity for bureaucratic, de-personalized decision making."*

*"Control should remain with the patient and those to whom control is granted by the patient, such as the family physician. The government does not need to own or control the information to improve info sharing/transmission."*

*"The files are managed in trust. The information is the client's."*

Among those who favoured a central agency approach the following was written:

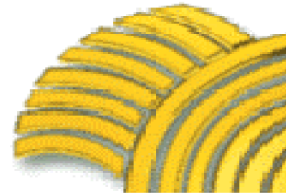
*"The provincial health department should 'own' the information and then 'delegate' certain authorities to the districts who can then further 'delegate'. Ultimately, the provincial health department must be accountable for enforcement of legislation."*

The need to define the responsibility for control of information through legislation was strongly supported in the written comments.

*"With the formation of health districts, and the centralization of outside agencies, the ownership issue becomes more of a concern, both to the facility it originated from and to the client."*

*"Yes, definitions of ownership should be clarified."*

*"Clarifying ownership roles may improve the handling of information."*



### **3. COLLECTION OF HEALTH INFORMATION**

Responses to questions about the collection of health information reflect the need to respect the individual's interest in their own health information.

#### ***Informed Consent***

- 99.3% indicated agreement with the statement: "Individuals should be informed about why information is being collected." (71.4% agreed strongly, 20% agreed, 7.9% agreed somewhat, 0% disagreed somewhat and 0.7% disagreed strongly.)

However, no clear preference emerged for how individuals should be informed:

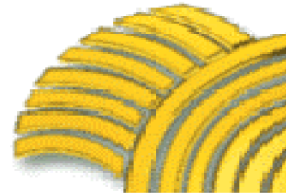
- 62.9% indicated a level of agreement that: "To receive informed consent, health professionals would need to provide details of every anticipated use of personal health information." (23.6% agreed strongly, 16.4% agreed, 22.9% agreed somewhat, 17.1% disagreed somewhat, 16.4% disagreed strongly and 3.6% offered no opinion.)
- 71.4% had agreement with the statement: "To receive informed consent, health professionals should not have to provide details of every anticipated use of personal health information on every occasion, but should be expected to make this information available on request and through pamphlets, brochures, and other convenient means." (18.6% agreed strongly, 37.1% agreed, 15.7% agreed somewhat, 11.4% disagreed somewhat, 12.9% disagreed strongly and 4.3% offered no opinion.)

The following statements reflect the differences of opinions:

*"I don't think people who are sick care to be burdened with details, but an effort must be made to keep people abreast of current practice. Those with language and literacy problems need special consideration."*

*"The specific purpose of collection should be explained to the patient, as well as why or how the information will be used. This should be done by briefing each time it is given to anyone other than the patient's doctor."*

*"This [general awareness] is very important. Detailed briefings are not likely possible or practical on each encounter, but there should be opportunity for a client to be briefed as needed."*



*"I believe it needs to be more than just brochures, acts, etc. Many people do not read these or for the population that is illiterate, cannot. The best approach would be a combination."*

*"An individual needs to know the purpose for collecting the health information, how it will be used, and any rights they have to limit use. Detailed briefings for each individual as they seek health services would be preferable, however, the man hours required for detailed briefing would only serve to bog down the health system and add additional expense to an already costly system. General awareness through brochures, newspaper ads, posters in medical offices, etc., could provide information sufficient to allow an individual to grant consent for use of health information."*

There was no consistent answer as to how consent should be granted. The following reflects a range of responses:

*"There needs to be clarification on this question, i.e. consent for treatment or consent for sharing information."*

*"Registering implies consent."*

*"Signed is best. Verbal OK in emergencies."*

*"Also must consider if consent can be given by individual who may not have properly considered ramifications of consent--informed consent."*

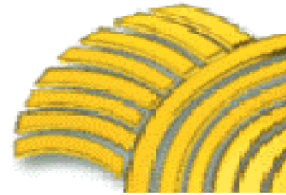
*"Yes--consent means a written, signed document whenever possible. Registering for a program does not indicate consent."*

*"Registering with the health system indicates consent!"*

### **Limiting Collection**

There was also support for limiting the collection of health information to only what is necessary.

- 89.3% indicated agreement with the statement: "Health professionals should limit the collection of information to only what is necessary for a purpose." (39.3% agreed strongly, 34.3% agreed, 15.7% agreed somewhat, 5.7% disagreed somewhat, 2.9% disagreed strongly and 2.1% offered no opinion.



## **Striking a Balance**

There was strong support for striking a balance between privacy and the need for information in the health system.

- 91.4% indicated a level of agreement with the statement: "It is important to balance the need to protect privacy with the need for the health system to collect the information necessary to provide and evaluate services." (38.6% agreed strongly, 42.1% agreed, 10.7% agreed somewhat, 2.9% disagreed somewhat, 2.9% disagreed strongly and 2.9% offered no opinion.)

## **Collection From the Individual**

There was also strong support for collecting health information directly from the individual, wherever possible and practical.

- 90.0% had some level of agreement that: "Wherever possible and practical, information about individuals should be collected directly from the individual the information is about." (40.0% agreed strongly, 34.3% agreed, 15.7% agreed somewhat, 4.3% disagreed somewhat, 2.9% disagreed strongly and 2.9% offered no opinion.)

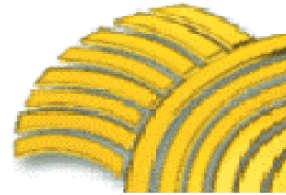
## **Right to Limit Use**

The responses indicated considerable support for individuals having the right to set certain limits on the use of personal information.

- 83.5% had some agreement with the statement that: "Individuals, in certain circumstances, should have the right to refuse to give certain information or to limit its use." (41.4% agreed strongly, 27.1% agreed, 15.0% agreed somewhat, 10.7% disagreed somewhat, 3.6% disagreed strongly and 2.1% offered no opinion.)

The following statements are representative of the written responses regarding limitation and use of information:

*"The legislation must go far enough to protect personal health information."*



*"Legislation can only do so much, the rest is up to the professionals in the health system. With legislation guidelines and proper education I believe collection and protection of info will be handled responsibly."*

*"The guiding principle should be that of doing no harm and that we do as much as necessary to have an efficient and effective health care system."*

#### **4. USES/ACCESS/DISCLOSURE**

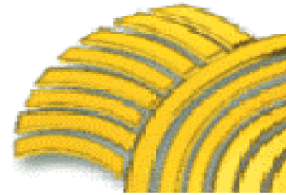
The questionnaire offered a series of statements regarding the use, access and disclosure of health information.

There was strong support for establishing limits on the use and disclosure of personal health information.

- 89.3% indicated agreement with the statement: "Health information should only be used for the purpose it was gathered, or for a consistent purpose." (43.6% agreed strongly, 37.1% agreed, 8.6% agreed somewhat, 3.6% disagreed somewhat, 2.9% disagreed strongly and 4.3% offered no opinion.)
- 90.7% indicated agreement with the statement: "Personal health information should only be disclosed with the individual's consent or in accordance with legislation." (49.3% agreed strongly, 34.3% agreed, 7.1% agreed somewhat, 3.6% disagreed somewhat, 2.9% disagreed strongly and 2.9% offered no opinion.)
- 92.2% indicated agreement with the statement that: "Only the information required for a specific purpose should be disclosed." (48.6% agreed strongly, 33.6% agreed, 10.0% agreed somewhat, 0.7% disagreed somewhat, 1.4% disagreed strongly and 5.7% offered no opinion.)

On the other hand, there was very strong support for making information available when required for treatment.

- 95.8% indicated agreement with the statement: "Health information necessary for treatment should be available to service providers when and where they need it." (58.6% agreed strongly, 29.3% agreed, 7.9% agreed somewhat, 1.4% disagreed somewhat, 1.4% disagreed strongly and 1.4% offered no opinion.)



- 89.3% indicated agreement with the statement: "Hospitals, district health boards, doctors offices and others should be able to exchange personal health information when it is important for health services." (51.4% agreed strongly, 28.6% agreed, 9.3% agreed somewhat, 5.0% disagreed somewhat, 2.9% disagreed strongly and 2.9% offered no opinion.)

There was strong support for legislative and policy regarding the management of health information.

- 96.5% indicated agreement with the statement: "It is important to provide legislative and policy direction for the management of health information." (63.6% agreed strongly, 28.6% agreed, 4.3% agreed somewhat, 0.7% disagreed somewhat, 0.7% disagreed strongly and 2.1% offered no opinion.)

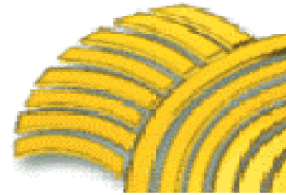
There was also strong support for controls on the sale or marketing of health information.

- 89.3% indicated agreement with the statement that: "Legislation should control the sale or marketing of health information." (78.6% agreed strongly, 9.3% agreed, 1.4% agreed somewhat, 0.7% disagreed somewhat, 5.0% disagreed strongly and 5.0% offered no opinion.)

The following reflect the comments provided:

*"The HSA [Hospital Standards Act] and Mental Health Services Regulations refer to when and to whom patient info shall be disclosed. These 'need to know' guidelines should be followed and introduced into the new legislation. We may need to further define 'need to know' including release of information to spouses, parents, children and outside agencies."*

*"Any definition of 'need to know' must necessarily include health care and/or support care givers, those with legal, including statutory authority, individuals accessing information about themselves. Unidentifiable individual information should be made available for research and statistical purposes providing that the nature of unidentifiable personal health information released cannot because of its unique nature be traced back to the individual it was collected from. Individuals without any involvement in the health care system and without any legal or statutory authority to access personal health information should not have access under any circumstances."*



*"Access should be given to those involved in the delivery of health care and statistical information should be available to policy makers."*

*"Doctors and nurses needing to render life-saving treatment to a patient unable to speak. 'Need to know' needs to be clarified with 'like to know'. Obviously the public should not have access to anyone else's health info at any time-- unless proper consent from the patient was obtained for an important reason; like tracing certain family history of disease and genetics."*

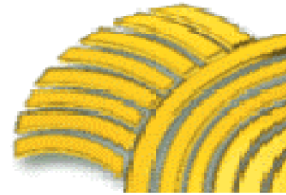
*"Employers should not have personal health information other than from a physical exam requested at the time of employment."*

## **5. INTEGRITY AND SECURITY OF HEALTH INFORMATION**

There was overwhelming support for measures to protect the integrity and security of health information.

- 98.6% indicated agreement with the statement: "Legislation should require that all health information systems incorporate the most stringent security policy and measures possible and practical." (79.3% agreed strongly, 15.0% agreed, 4.3% agreed somewhat, 0% disagreed somewhat, 0% disagreed strongly and 1.4% offered no opinion.)
- 96.4% had some level of agreement that: "There should be limitations on who can input or alter data, and on who can review or use specific data." (76.4% agreed strongly, 20.0% agreed, 1.4% agreed somewhat, 0.7% disagreed somewhat, 0% disagreed strongly and 1.4% offered no opinion.)
- 99.3% indicated agreement with the statements: "Electronic transmission of health information must be secure. Systems must be designed to prevent unwanted access." (87.9% agreed strongly, 10.0% agreed, 1.4% agreed somewhat, 0% disagreed somewhat, 0% disagreed strongly and 0.7% offered no opinion.)
- 97.9% indicated agreement with the statement that: "Policy, procedure and training must be in place to ensure that employees in the health system know their responsibilities to protect personal health information." (87.1% agreed strongly, 10.0% agreed, 0.7% agreed somewhat, 0% disagreed somewhat, 0% disagreed strongly and 2.1% offered no opinion.)





- 98.6% indicated agreement that: "Wherever possible, the system should have audit trails to monitor access and use of personal health information." (83.6% agreed strongly, 12.1% agreed, 2.9% agreed somewhat, 0% disagreed somewhat, 0% disagreed strongly and 1.4% offered no opinion.)
- 90.7% supported the statement that: "Destruction of health information, regardless of format, should be executed in a secure fashion." (73.6% agreed strongly, 15.7% agreed, 1.4% agreed somewhat, 1.4% disagreed somewhat, 1.4% disagreed strongly and 6.4% offered no opinion.)

There was general support for addressing security issues in legislation. However, there was no consistent opinion on what the legislation should do. The following comments offer some examples:

*"Policies may be changed according to need without delays created by changing legislation. Legislation should be established to support policies that establish standards and protect information. Policies could also be covered under 'Rules and Regulations'."*

*"Yes certain elements of security could be included, such as, individual security codes policy, acknowledge system monitoring (paper trail, date and time of access, audit trail, quality assurance checks). Include penalties for abuse, misuse or unauthorized disclosures."*

*"Security must be developed outside of legislation as the latter is too inflexible."*

*"Security policy must be included in legislation."*

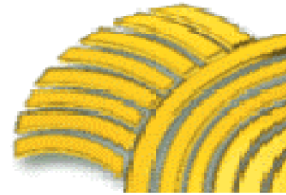
The following comments were among those offered regarding the destruction of personal health information:

*"Destroy some files (after 10 year retention). Pertinent important info, i.e., physician history/examination, pathology, xray, MRI, etc., and such are important ongoing information for research and also family history."*

*[Records retained for historical or research purposes] "must be unidentifiable."*

*"Registry and personal information needs to be maintained for historical/research purposes. In my opinion, microfilmed/electronically stored records take up very little room and should never be destroyed. The information is important for personal and family health care purposes in the future. For example, hereditary illnesses, family*





*history documentation. Technology must be present in the future to be able to 'read' the images that have been stored (microfilm, imaging, etc.)"*

*"Yes - information that can help to design good public health policy should be retained."*

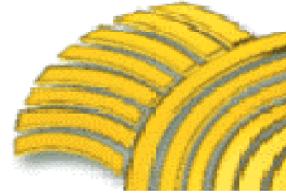
*"The record must be destroyed and only aggregate statistical information should remain."*

*"The health information should never be destroyed as they would be required for family history, genetic studies and historical purposes. Files could be preserved through microfilming and micro-imaging."*

## **6. ACCOUNTABILITY, COMPLAINTS AND COMPLIANCE**

There was strong support for statements regarding accountability and compliance in the system. However, there was no consensus on appropriate penalties.

- 97.1% agreed or agreed strongly that: “Organizations managing health information should develop policy and procedures to ensure compliance with legislation and to meet standards for proper management and protection of health information.” (75.0% agreed strongly, 22.1% agreed, 2.1% agreed somewhat, 0% disagreed somewhat, 0% disagreed strongly and 0.7% offered no opinion.)
- 87.9% agreed or agreed strongly that including penalties in legislation would make it more effective. (59.3% agreed strongly, 28.6% agreed, 9.3% agreed somewhat, 0% disagreed somewhat, 0.7% disagreed strongly and 2.1% offered no opinion.)
- 33.6% offered no opinion about the statement: “Maximum penalties should be fines up to \$1,000 or three months imprisonment.” (9.3% agreed strongly, 11.4% agreed, 17.9% agreed somewhat, 15.0% disagreed somewhat, 12.9% disagreed somewhat, 12.9% disagreed strongly and 33.6% offered no opinion.)
- 32.1% offered no opinion about the statement “Maximum penalties should be fines significantly higher than \$1000 or three months imprisonment.” (23.6% agreed strongly, 11.4% agreed, 17.9% agreed somewhat, 15.0% disagreed somewhat, 12.9% disagreed somewhat, 6.4% disagreed strongly and 32.1% offered no opinion.)



- 86.4% indicated support for the statement: “Health system employees should not suffer legal consequences for actions taken in good faith (in the belief that they were in compliance with the legislation) in the performance of duties.” (33.6% agreed strongly, 32.1% agreed, 20.7% agreed somewhat, 7.1% disagreed somewhat, 2.1% disagreed strongly and 4.3% offered no opinion.)

### Accountability and Penalties

In the written responses there was agreement that having policy to support the legislation, combined with penalties for violations, should result in compliance, openness and confidence in the system. There was recognition that this will, of course, depend upon what might be written into legislation, and there were questions about how legislation could be enforced.

When struggling with the difficult question of penalties, the responses were varied. Here are some examples:

*“It could help somewhat. It will make people think twice about inappropriate use.”*

*“Penalties should match the impact that the infraction has on the individual.”*

*“May reduce hallway gossip”*

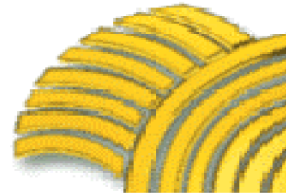
*“While fines and imprisonment have never proven to be a cure for criminal activity, they are the best weapons we have available to fight criminal activity. A maximum fine of up to \$50,000 or minimum of one-year imprisonment might better serve as a deterrent to abuse of personal health information.”*

### Complaint Mechanism

An important aspect of ensuring accountability is to have mechanisms for public complaints. The questionnaire asked a number of questions about what process might work best. The following examples reflect the range of answers:

*“Need to have a separate public office to investigate information violations. A separate perspective from the institutions must be made available to the client.”*

*“We probably do not need any additional watchdogs – the number of complaints will probably not be excessive.”*



*“Potential complaints could be handled through the FOI [Freedom of Information] Commissioner or the Ombudsman, however, both complainants and the health care system would be better served by having a public office tht deals exclusively with complaints elating to the health system.”*

*“Go first to the local institution. Probably appropriate to give access to F of IC [FOI or information and Privacy Commissioner] or Ombudsman.”*

*“If the legislation for health information follows the same principles ad FOIP [Freedom of Information and Protection of Privacy], it would make sense for the agency which has been overseeing that legislation (a Commissioner or Ombudsman), to oversee that health legislation – because they are already familiar with the basic principles and have experience in interpreting this type of legislation.”*

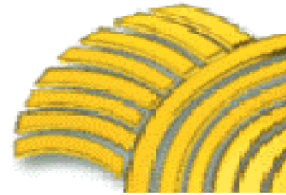
## **7. WHO SHOULD LEGISLATION APPLY TO?**

There was very strong support for including private practitioners in legislation.

- 90% of respondents supported the statement that: "Private practitioners should be included in legislation." (58.6% agreed strongly, 26.4% agreed, 5.0% agreed somewhat, 2.9% disagreed somewhat, 1.4% disagreed strongly and 5.7 offered no opinion.)
- 87.1% indicated agreement with the statement: "Legislation should regulate all management of personal health information." (54.3% agreed strongly, 27.1% agreed, 5.7% agreed somewhat, 4.3% disagreed somewhat, 0.7% disagreed strongly and 7.9% offered no opinion.)
- 17.2% supported the statement: "Private practitioners should only be regulated by professional practices and governing bodies." (2.9% agreed strongly, 10.7% agreed, 3.6% agreed somewhat, 21.4% disagreed somewhat, 50.7% disagreed strongly and 10.7% offered no opinion.)

The following is a sample of the written replies:

*"While I don't want more legislation, if it comes, it should apply to private practitioners too."*



*"Health information systems, legislation, policies, etc. should apply to all professionals. Try to establish one set of rules rather than one set for one group and another set for another group. Most rules should be common in nature."*

*"I believe this legislation should apply to private practice. Professional regulating bodies should have complementing regulations, e.g., professional misconduct."*

*"Private practitioners have their oath of confidentiality. I think it is understood by the public that this has performed its purpose well for the most part and I can't see much sense in changing this."*

*"The private sector needs to be regulated through legislation. Legislation should apply to all sectors having access to information, and therefore all sectors must follow the same rules to provide consistency."*

## **GENERAL**

### **Legislative Action**

- 75% of respondents answered positively that the protection of health information is important enough to warrant legislative action. Only 2% said no, while 23% offered no opinion or the opinion was not clearly for or against.

While most answers to this question were "Yes" or "Absolutely", some were more detailed:

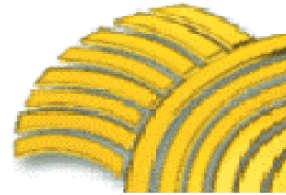
*"Yes. Some people have a lot to lose if confidential information was disclosed. e.g. HIV status."*

*"Yes, existing legislation is scattered and not clear. There are different rules for different areas, i.e., mental health versus hospital standards. Needs to be more uniform & all encompassing."*

*"Such protection is very important--too much so to trust to government."*

*"Depends on the legislation. If it's too restrictive, we don't need it."*

*"Most definitely. Thousands of people put their trust in the health system everyday. We need to ensure this information will be handled/used in the most appropriate manner."*



*Effective, efficient patient care is the objective and a system must be in place to accomplish this."*

*"Yes along with public education."*

*"Yes. This is especially true with the advancements in technology where electronic media have become the norm for transferring information. There is a definite balancing act as to what information to protect and the reasons for this protection."*

*"Yes, but the legislation should also mandate the use of this data to improve health and health care delivery."*

*"Yes, if it also protects the access to and uses of the information for public interest purposes."*

### **Other Issues and Ways to Address Issues**

The questionnaire asked if the list of issues was complete and what approaches can be used to address the issues. The following is a sample of the replies.

*"Public forums could be used."*

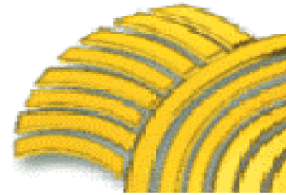
*"I still don't understand or know what your policy is regarding health research and data linkage."*

*"Whether the handling of personal genetic information will require special legislative measures will be an important matter for broad public discussion."*

*"Input from a variety of professional and consumer/advocacy groups to guide the development of practise and standards."*

### **Limiting the Use of the Health Services Number**

- 54% indicated support for limiting the Health Services Number (HSN) to health purposes only. 7% were not supportive, and 39% offered no opinion or were neither for nor against such action.



In most cases the answers were "Yes" or "No", but the following offers additional insight:

*"Legislation to limit the use of the Health Services Number is 'after the fact'. You have indicated the number is used as ID for credit and other purposes. With this in mind, restricting it to strictly health purposes is unrealistic."*

*"Yes, legislation should limit the HSN to only health purposes."*

*"I see the HSN as being similar to the federal SIN. There has to be some way to register people and for some the HSN is the only form of ID they have. The number, if used by those outside the health community, should only access Registry information and nothing else."*

### **GENERAL COMMENTS**

The following is a sample of general comments offered at the end of the questionnaire.

*"In balancing between the health needs of the individual, efficient delivery of care and the need for protection of information, the emphasis should be on sharing information more freely, at the risk of possibly releasing unnecessary information."*

*"The questionnaire does not seem to identify, as well as it might, the positive reasons for others--under clearly defined, well-controlled situations, to have access. The emphasis on the individual patient and privacy is important, but an emphasis on the positive reasons (physician practice monitoring; cost-of-service monitoring; research on a wide range of issues; disease monitoring; public safety) for access also bear identifying...."*

*"Thank you for the opportunity for input."*

### **CONCLUSION**

The response to the consultation indicates a significant interest in and concern for the protection of personal health information. Many responses offered a clear direction for public policy. In other cases, the fine balance between protection of privacy and use of the information has been demonstrated.

Saskatchewan Health is grateful to everyone who provided input into this important public policy. The responses have played a significant part in the review of legislation and in the drafting of proposed legislation further protecting personal health information.