

**OIPC  
Stakeholder  
Survey,  
2003**

**Highlights  
Report**

**March 2003**



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## Executive Summary

### ***Albertans attach high importance to the protection of personal privacy. Growing levels of concern regarding the privacy of personal information***

- Respondents overwhelmingly agree that it is important to protect individual privacy in Alberta (98% agree), an increase of 10% from the 2000 benchmark survey
- Nearly three-quarters (74%) of respondents are concerned that the privacy of personal information is at risk in Alberta, a significant increase from the 56% recorded in the 2000 survey
- Eighty-two per cent of respondents are concerned about the privacy of their own personal information, an increase of 11% from the 2000 survey
- Eighty-three per cent of Albertans are more concerned about the privacy of their own personal information than they were five years ago, an increase from the 76% recorded in 2000. Sixty-one per cent of respondents strongly agree with the statement, essentially the same level recorded in 2000

### ***Albertans believe it is important to keep various types of personal information private and safe. Financial and health records rank as highest priorities***

- Top-tier information record:
  - Credit card numbers (98%)
  - Accounts in financial institutions (96%)
  - Credit reports (93%)
  - Personal health records (89%)
- Middle-tier information records:
  - Government benefits (83%)
  - Government registries (80%)
  - Email messages on the Internet (79%)
- Lower-tier information records:
  - Shopping information over the Internet (69%)
  - Internet surfing history (68%)
  - Donations to charities (65%)
  - Utility bills (64%)

### ***Relatively low level of awareness of personal information laws***

- Thirty-eight per cent of respondents are aware of laws intended to protect their personal information, while 60% are unaware. This compares to awareness/lack of awareness ratings of 39% and 56% respectively, from the 2000 benchmark survey

- Of those who express some awareness with personal information protection laws, Alberta's Freedom of Information and Protection of Privacy (FOIP) Act received the most frequent mention at 54%, a marginal decline from the 2000 survey
- Beyond FOIP, Albertans have relatively weak awareness of other laws intended to protect their personal information. Alberta's Health Information Act (HIA) ranks second among laws cited by respondents at 6%. This represents a decline from the 17% recorded in the 2000 survey

***Very high importance attached to regulating private sector's use of personal information. Financial and employee record generally rank highest in importance***

- Albertans attach very high importance (93%) to regulating the private sector's use of personal information
- Support levels for elements that should be included in legislation designed to regulate the private sector's use of personal information:
  - Information collected by financial institutions (92%)
  - Information collected by an employer (85%)
  - Information collected from customers by business (81%)
  - Information collected from members by professional organizations and clubs (77%)
  - Information collected by businesses when you contact them through the Internet (74%)
  - Information about your Internet and telephone usage collected by your employer while you are at work (66%)

***High level of attention paid to the privacy and confidentiality of personal health information. Role of health custodians in keeping personal health information confidential deemed to be extremely important***

- Nearly three-quarters (71%) of respondents indicate that they personally pay some or a lot of attention to issues around the privacy and confidentiality of personal health information
- Albertans attach considerable importance to the role of health custodians in keeping their personal health information confidential. Physicians (90%), hospitals and nursing homes (89%), pharmacies or pharmacists (88%), and Alberta Health and Wellness (87%) all considered to play very important roles in keeping personal health information, private

***Albertans attach considerable importance to the exercise of individual consent when considering disclosure of their personal health information to custodians***

- I would agree that my consent be required before my health information is disclosed to someone doing health research (89%)
- I would agree that my consent be required before my health information is disclosed to law enforcement officers (86%)
- I would agree to my health information being disclosed to Alberta Health and Wellness for planning and resource allocation (71%)
- I would agree to my health information being disclosed without my consent to researchers (69%), provided that any information that could identify me has been removed
- I would agree to my health information being used for public health surveillance, which includes monitoring of communicable diseases and assessing lifestyle influences such as smoking (68%)
- I would agree to my health information being released without my consent to governments, provided that any information that could identify me has been removed (63%)

***Relatively low levels of familiarity with the HIA***

- Over five-in-ten (53%) Albertans say they have heard about the HIA. Awareness of the HIA is linked to level of attention paid to the privacy and confidentiality of personal health information and the level of familiarity and satisfaction with the OIPC
- Forty-one percent of those Albertans who have heard about the HIA say are familiar with it, indicating either a low level of knowledge with the scope and content or of the Act, or little experience in utilizing the Act

***High satisfaction/dissatisfaction rating on role of HIA in protecting privacy of personal information among aware Albertans. However, significant numbers of aware Albertans register no opinion***

- Of those who have heard about the HIA, nearly four-in-ten (39%) are satisfied with the effectiveness of the HIA in protecting the privacy of personal health information, while just 11% are dissatisfied
- However, four-in-ten (40%) of those who have heard about the Act are neither satisfied or dissatisfied

***Limited use of HIA to access personal health information***

- Twenty-two percent of respondents who are aware of the HIA have used the Act to access their personal health information
- Seventy-seven percent of respondents have never used the Act to request access to their personal health information

***Public relies on various sources of information about HIA. Traditional sources (i.e. physicians and newspapers) most mentioned***

- Physicians (37%) and newspapers (33%) are the primary sources of information about the HIA
- A middle tier of communications vehicles –television (26%), Internet (22%), pharmacies (20%), Alberta Health and Wellness (19%), radio (18%), word of mouth (17%), and work or job (16%) – relied upon less frequently
- Specialized communications sources, such as the OIPC (5%), cited infrequently as sources of information about the Act

***Strong support among Albertans for placing personal health information in an electronic health record (EHR) for treatment purposes***

- Over eight-in-ten Albertans (82%) believe it is moderate to very appropriate to have personal health information placed in an EHR that can be accessed whenever treatment is sought by the individual
- Fifty-eight per cent of respondents believe it is appropriate to very appropriate
- Just 16% of Albertans believe that use of an EHR in treatment is an inappropriate use of personal health information

***High level of support for exercise of personal consent on who can obtain access to an EHR***

- Eighty-nine per cent of respondents believe it is important for the individual to exercise consent on who can obtain access to their EHR

***Level of support for disclosure, without consent, of personal health information through an EHR linked to relationship with and proximity to health provider***

- Doctor or other health care provider involved in my treatment (72% agree)
- Health care provider involved in my treatment within Alberta (69% agree)
- Health care provider involved in my treatment within my health region (69% agree)
- Health care provider involved in my treatment within Canada (63% agree)
- Health care provider for secondary purposes such as health system management (35% agree)

***List of concerns about EHRs topped by unauthorized access to personal health information***

- Unauthorized access to EHRs highest concern mentioned by Albertans at 37%
- Followed by a second tier of concerns – hackers (21%)
- Lower level of concern – loss of information (7%), system failure (6%), and computer theft (5%)
- Twenty-two per cent of respondents mentioned all of the above concerns

***Legislation to protect the privacy of health information should include both the public and private sectors***

- Albertans clearly support legislation that protects the privacy of health information in both the public and private sector, equally (82%).

***Relatively low levels of familiarity with the OIPC***

- Just 17% of respondents are somewhat or very familiar with the OIPC, while 83% are not at all or not very familiar
- Familiarity with the OIPC linked to level of attention to the privacy and confidentiality of personal health information and awareness of the HIA

***Mixed assessment of independence of OIPC***

- Thirty-five per cent of respondents believe the OIPC operates independently from government, while 31% of respondents believe that the organization is not arms-length from government
- Significant number of Albertans (34%) are unable to express an opinion one way or the other

**Overall satisfaction with the OIPC is mixed. However, many Albertans are unable to express an opinion**

- Overall level of satisfaction with the performance of the OIPC is 21%, while the level of dissatisfaction is 24%
- Mandate and mission of organization does not seem to well understood by Albertans – 48% of respondents are neither satisfied nor dissatisfied with the OIPC

**Most Albertans want to know more about what the OIPC does**

- Nearly eight-in-ten Albertans (79%) want to know more about the OIPC

**Rapid evolution of privacy field informs next steps**

- The following areas have been identified as requiring further exploration in subsequent surveys:
  - The link between support for the exercise of individual consent regarding disclosure/use of personal health information and the relationship with and level of trust in custodians
  - The link between awareness, understanding, use and support of the HIA and the OIPC and the readiness of custodians to provide access to personal information to individuals without resort to the legislative and regulatory framework
  - The nature of the relationship and the level of trust in the role of the custodian involved in the protection, collection, use and disclosure of personal information
  - Views and attitudes of Albertans towards the disclosure/use of personal health records by health providers for treatment purposes
  - Views and attitudes of Albertans familiar with the OIPC regarding the independence and accountability of the organization
  - Levels of awareness, understanding and use of the HIA and EHRs by custodians as defined under the Act
  - Views and attitudes of Albertans regarding the collection, use and disclosure of personal information by private sector organizations in Alberta, i.e. Personal Information Protection Act



- Views and attitudes of Albertans towards new developments in the field of personal health information

## 1.0 Study Background and Understanding

The Office of the Information and Privacy Commissioner of Alberta (OIPC) is an independent office of the Legislative Assembly of Alberta. Through the auspices of the Commissioner, the Office's mandate includes overseeing the access and privacy provisions of the *Freedom of Information and Protection of Privacy Act* and the *Health Information Act*, and to inform and educate the public about access and privacy issues.

The OIPC is interested in assessing Albertans' awareness and understanding of privacy issues in general, and the Alberta Health Information Act (HIA), in particular. The HIA was passed by the Alberta legislature on December 9, 1999 and proclaimed into force by the Minister of Health and Wellness on April 25, 2001. With the HIA being in operation for nearly two years, the OIPC is seeking an assessment of the views of stakeholders, including: the level of awareness and understanding of the Act; the role of custodians; issues around the exercise of consent, access, disclosure, and use of personal health information and electronic health records (EHRs).

As part of this exercise, the OIPC contracted GPC International to conduct a research study with the general public across the province of Alberta. A 20-minute telephone survey of 1,004 Albertans (600 urban, 404 rural) was conducted between March 15 and March 28, 2003, the purpose of which was to:

- Measure general attitudes and perceptions towards privacy issues and legislation;
- Measure awareness, understanding, use of, and level of support for Alberta's Health Information Act (HIA);
- Assess orientations around such issues as the collection, use of, and consent to disclosure of health records by custodians;
- Measure general views and concerns regarding the disclosure/use of electronic health records (EHRs) and access to EHRs;
- Views on the role of the OIPC in administering and communicating the HIA; and
- Measure changes in general attitudes and perceptions toward general privacy issues derived from 2000 benchmark survey.

GPC envisions this stakeholder perception survey as establishing guideposts for the OIPC in the development and implementation of communications strategies around the HIA, as well as identifying potential areas that could guide a future legislative review of the Act as issues around the privacy of personal information continue to evolve.

With a sample of 1,004 Albertans, the results at the provincial level are accurate to within +/- 2.5%, 19 times out of 20. Margins of error are larger when results are analyzed at sub-provincial levels.

The image shows the cover page of a report. At the top, there is a world map graphic. Below the map, on the left, is the GPC logo (a blue circle with 'GPC' in white) and the text 'GPC International Public Affairs & Communications'. To the right of this is the text 'A Fleishman-Hillard Company' and a collage of small images showing people and a globe. The main title of the report is 'Office of the Information and Privacy Commissioner' in large blue font, followed by 'Findings From a Survey of Albertans' in a slightly smaller blue font. At the bottom of the page, the date 'March 2003' is printed in blue.

## 2.0 General Views on Privacy Issues

Albertans surveyed overwhelmingly agree that it is important to protect individual privacy in Alberta (98% agree), an increase of 10% from the 2000 benchmark survey. Support is strong across all demographic groupings, as well as attitudinal orientations. Eighty-four per cent strongly agree with this statement, compared to 74% strong agreement in 2000. Strong agreement is particularly prevalent among older Albertans (age 55-64) (87%) and those familiar with the OIPC (90%), while weaker among those who pay little or no attention to the privacy and confidentiality of personal health information.

Albertans are concerned about issues relating to protection of individual privacy, despite a relatively low level of awareness and understanding of various legislative initiatives in the area.

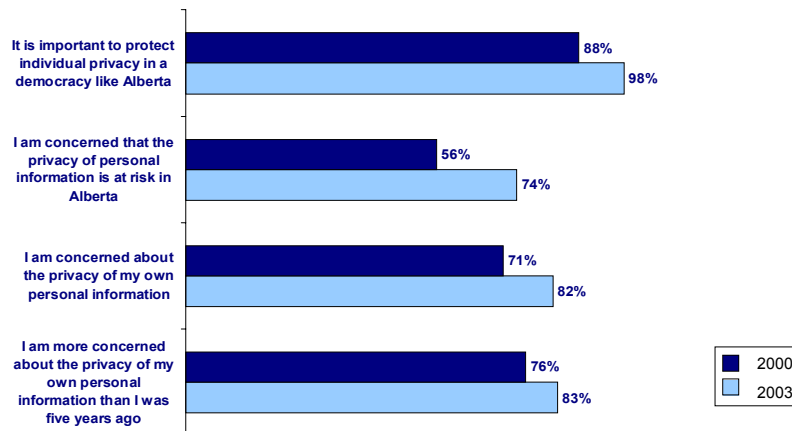
Nearly three-quarters (74%) of respondents are concerned that the privacy of personal information is at risk in Alberta, an increase from the 56% recorded in the 2000 survey. Concern is particularly prevalent among middle-aged Albertans (age 35-44) (78%) and those familiar with the OIPC (79%), with weaker concern expressed by those who pay little or no attention to the privacy and confidentiality of personal health information (59%).

Eight-two per cent of respondents are concerned about the privacy of their own personal information, an increase of 11% from the 2000 survey. Support is generally consistent across most demographic and attitudinal variables, although there is a weaker level of concern among those who pay little or no attention to the privacy and confidentiality of personal health information (71%).

Eighty-three per cent of Albertans are more concerned about the privacy of their own personal information than they were five years ago, an increase from the 76% recorded in 2000. 61% of respondents strongly agree with the statement, essentially the same level recorded in 2000. The level of strong agreement is generally consistent across all demographic and attitudinal categories, with the notable exception of university-educated (49%) and those who pay little or no attention to the privacy and confidentiality of personal health information (49%).

## Perceptions on Privacy Issues

I'm going to read you a series of statements and for each, I'd like you to tell me whether you strongly agree, somewhat agree, or strongly disagree with the statement. (% saying agree)



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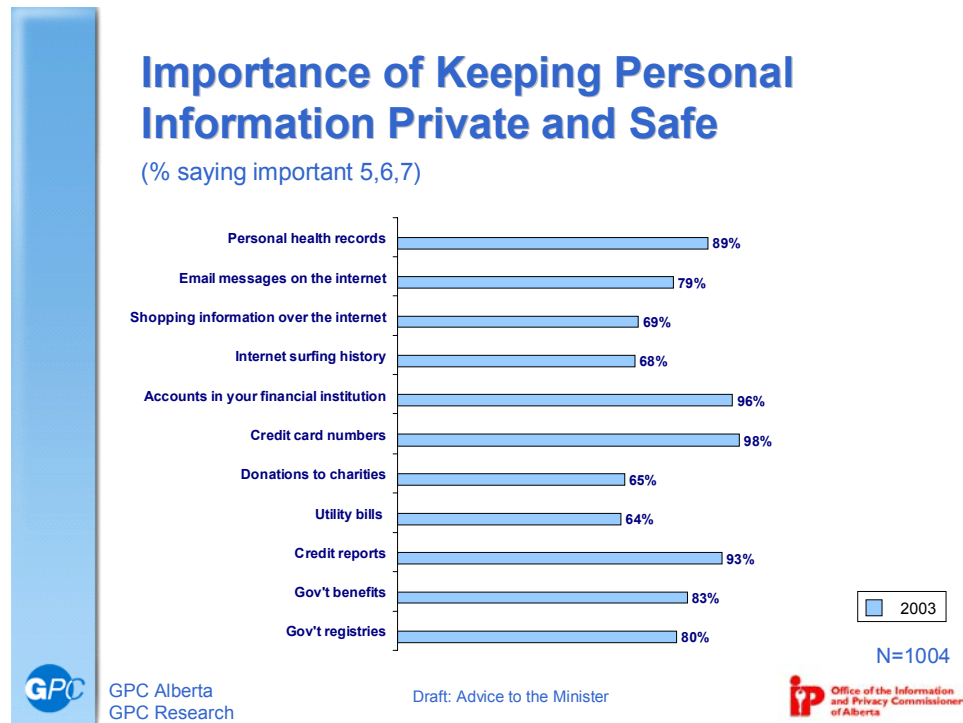
Draft: Advice to the Minister



Albertans ascribe considerable importance to keeping various types of personal information private and safe.

Sensitive personal financial and health records constitute a first-tier of records, generating the most agreement from respondents:

- Credit card numbers (98%)
- Accounts in your financial institution (96%)
- Credit reports (93%)
- Personal health records (89%)



The importance of keeping these types of records private and safe is very consistent across all demographic and attitudinal categories, with one notable exception. With respect to personal health records, there is a significant distinction in support between those who pay little or no attention (77%) and those who pay some or a lot of attention (95%) to the privacy and confidentiality of personal health information.

A second-tier of personal information includes government-related records and electronic mail:

- Government benefits (83%)
- Government registries (80%)
- Email messages over the Internet (79%)

Of interest, seniors and those with a high school or less education generally are somewhat less inclined to attach considerable importance to keeping these second-tier personal records private and safe when compared with the provincial average.

Type of personal record, 2003	Overall rankings % describing as important (5, 6, 7 on a 7-point scale)	Seniors % describing as important (5, 6, 7 on a 7-point scale)	High school or less % describing as important (5, 6, 7 on a 7-point scale)
Government Benefits	83	79	78
Government Registries	80	73	81
Emails on the Internet	79	56	71

A third tier of personal information records to keep private and safe in order of importance to Albertans, includes:

- Shopping information over the Internet (69%)
- Internet surfing history (68%)
- Donations to charities (65%)
- Utility bills (64%)

Of interest, there are distinctions in importance attached to these personal records based on the level of familiarity with the OIPC, as illustrated below.

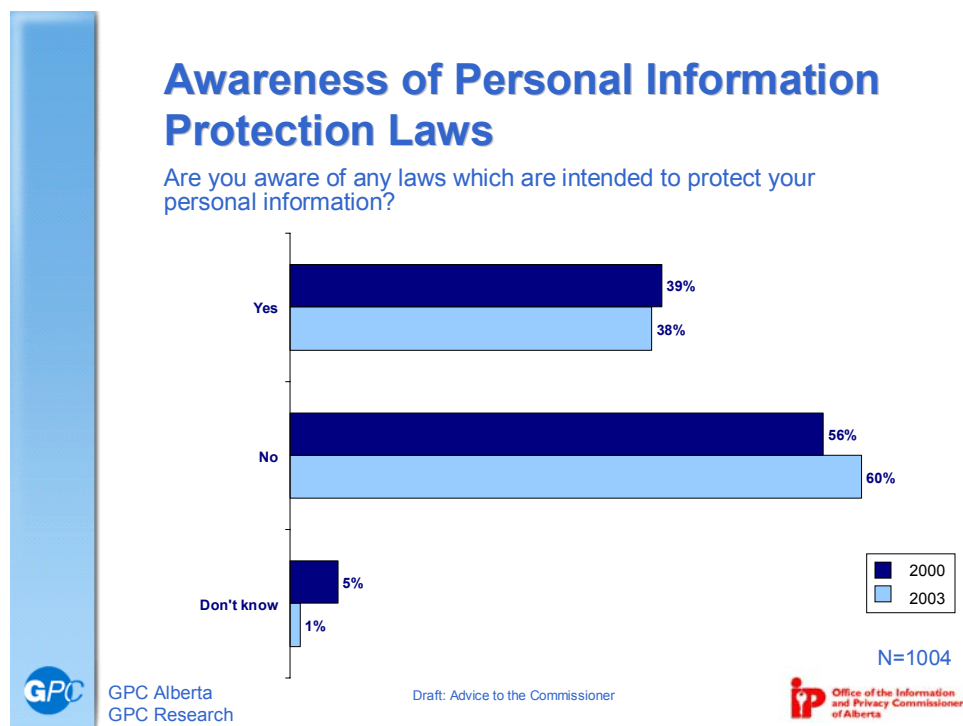
Type of personal record 2003	Overall rankings % describing as important (5, 6, 7 on a 7-point scale)	Those familiar with the OIPC % describing as important (5, 6, 7 on a 7-point scale)	Those unfamiliar with the OIPC % describing as important (5, 6, 7 on a 7-point scale)
Shopping information over the Internet	69	75	68
Internet surfing history	68	75	66
Donations to charities	65	71	64
Utility bills	64	72	63

### 3.0 Personal Information Protection Laws

Given the rising concern that Albertans have about privacy issues and the importance they attach to keeping personal information safe and private, it is notable that there is still a relatively low level of awareness of laws designed to protect the privacy of personal information.

Thirty-eight per cent of respondents are aware of laws intended to protect their personal information, while 60% are unaware. This compares to an awareness/unawareness rating of 39% and 56% respectively, from the 2000 benchmark survey

The level of awareness of personal information protection laws is higher among middle aged Albertans (age 45-54) (45%), those with a university education (51%), and those who have heard about the OIPC (62%). Low levels of awareness are exhibited by seniors (24%), those with high school or less education (28%), retired Albertans (28%), and those unfamiliar with the OIPC (34%).



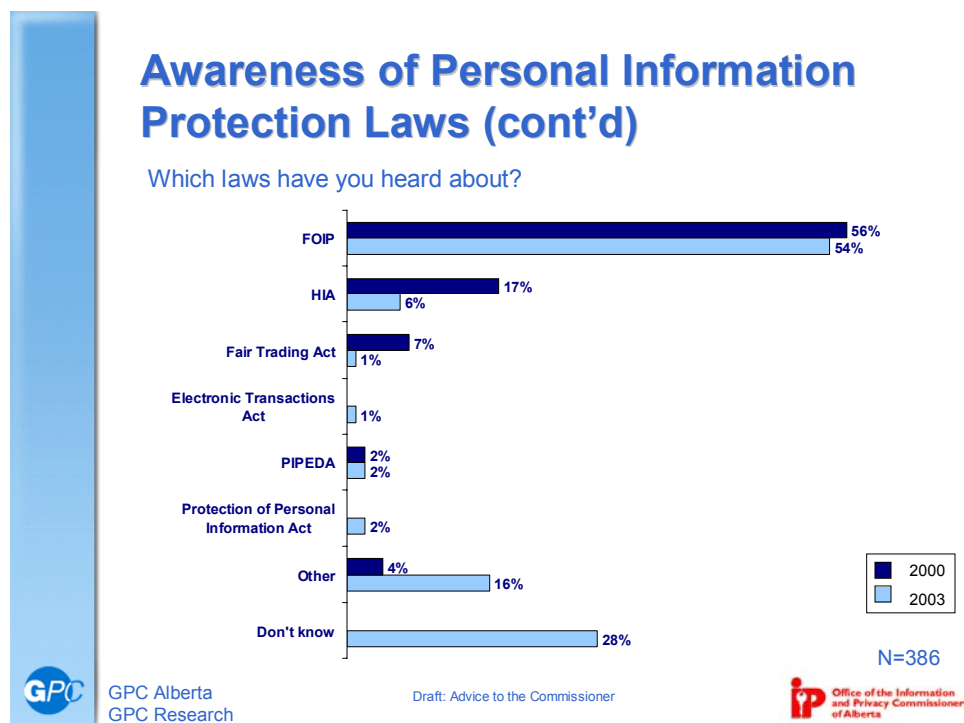


Of those who expressed some awareness with personal information protection laws, Alberta's Freedom of Information and Protection of Privacy (FOIP) Act received the most frequent mention at 54%, a marginal decline from the 2000 survey.

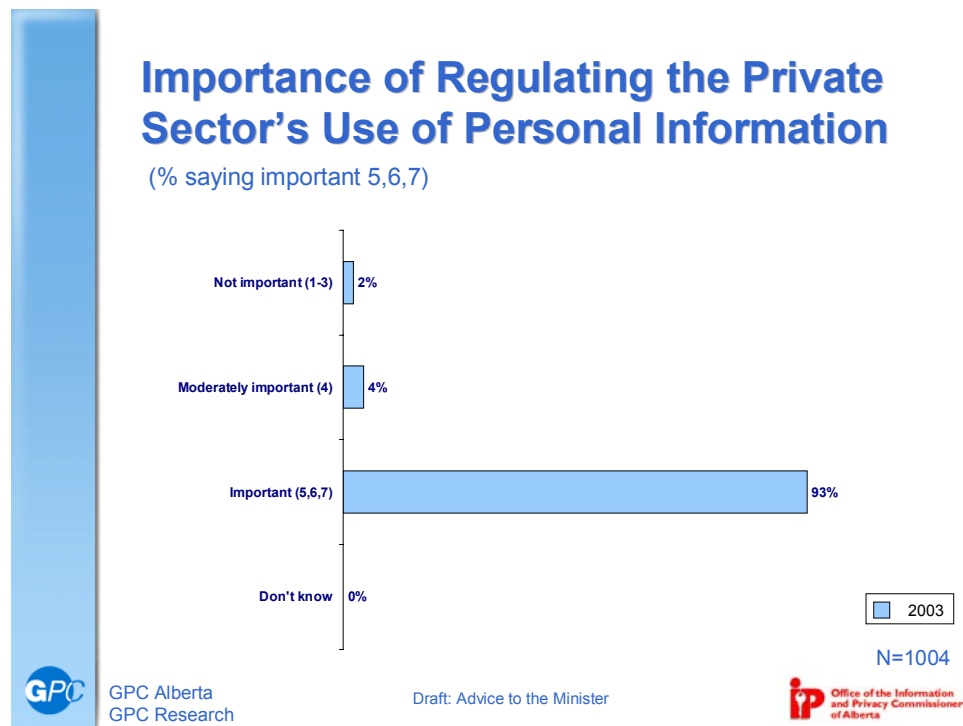
Females (60%) are more familiar with FOIP than males (47%). Awareness of FOIP is also linked to the level of familiarity with the OIPC. Those familiar with the OIPC have a 63% level of awareness of FOIP, compared to 51% among those who were not familiar with the Office.

Beyond FOIP, Albertans have relatively little awareness of other laws intended to protect their personal information. Alberta's Health Information Act (HIA) ranks second among laws cited by respondents at 6%. This represents a significant decline from the 17% recorded in the 2000 survey. It is likely that the decline in awareness of the HIA can be attributed to the time period that has elapsed since the bill received significant media attention. At the time the 2000 survey was conducted, the legislation had just recently been debated and passed in the Alberta Legislature. As well, during the period in which the 2000 survey was conducted, there was considerable public attention being paid to the *Health Care Protection Act*.

The level of awareness of the HIA is somewhat higher among seniors (19%) and those with a university education (10%). There is also some distinction in awareness among those who pay some or a lot of attention to the privacy and confidentiality of personal health information (8%) versus those who pay little or no attention (2%).



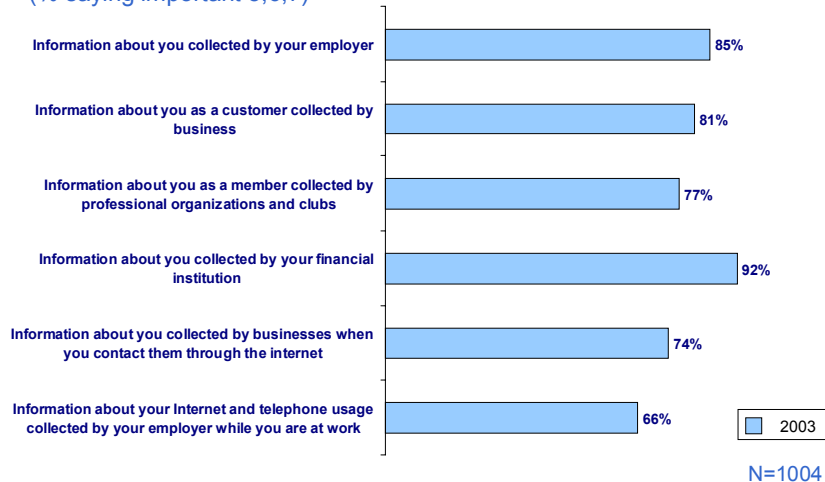
Despite relatively low levels of awareness of personal information protection legislation, Albertans attach significant importance (93%) to regulating the private sector's use of personal information. The level of importance is consistent across all demographic and attitudinal categories, with some distinction between those who pay some or a lot of attention to the privacy and confidentiality of personal health information (95%) versus those who pay little or no attention (86%).



When asked to assess the importance of various elements that should be included in legislation designed to regulate the private sector's use of personal information, Albertans attach the greatest importance to information collected by financial institutions (92%), followed by information collected by an employer (85%). A middle-tier of elements is information collected from customers by businesses (81%) and information collected from members by professional organizations and clubs (77%). A lower-tier of elements includes information collected by businesses who are contacted by individuals through the Internet (74%) and information collected by an employer about an employee's Internet and telephone usage (66%).

## Importance of Privacy Legislation Elements

(% saying important 5,6,7)



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Draft: Advice to the Minister



The following table highlights demographic and attitudinal variations regarding the level of importance for each of the proposed elements of legislation regarding the use of personal information by the private sector, focusing on those groups that tend to express higher or lower than average levels of importance, or where significant distinctions in importance arise.

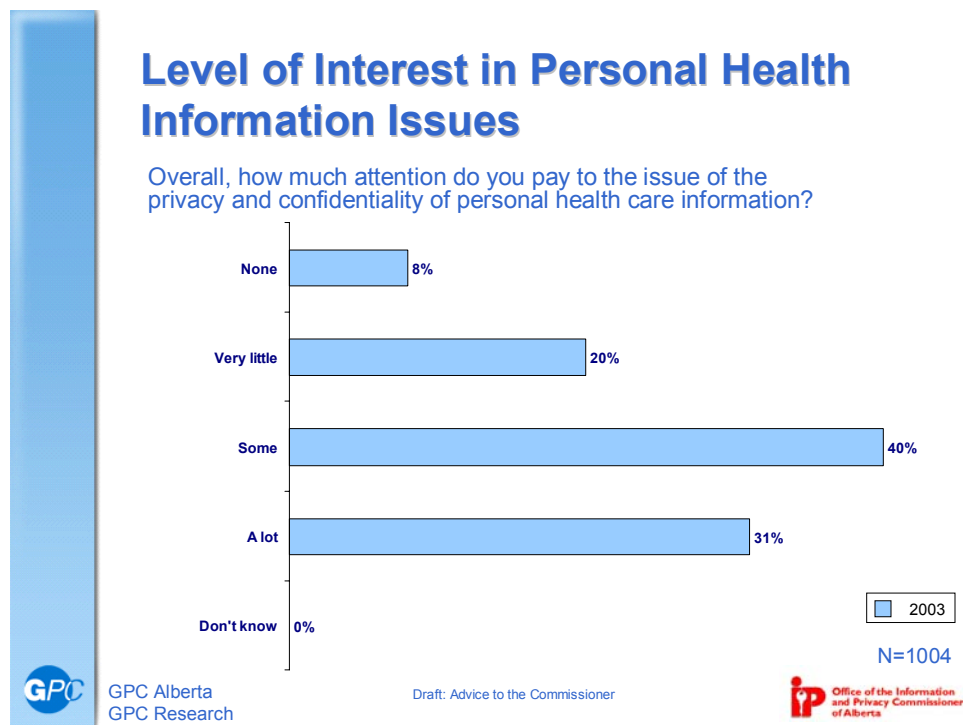
<i>I would like you to tell me, how important it is to you to have such legislation include the following:</i>	<b>Demographic and attitudinal variations % saying important (5,6,7)</b>
Information about you collected by your financial institution (92%)	Some or a lot of attention paid to the privacy and confidentiality of personal health information (94%) Little or no attention paid to the privacy and confidentiality of personal health information (88%)
Information about you collected by your employer (85%)	Seniors (71%) Retired Albertans (73%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (88%) Little or no attention paid to the privacy and confidentiality of personal health information (77%)

Information about you as a customer collected by business (81%)	Some or a lot of attention paid to the privacy and confidentiality of personal health information (86%) Little or no attention paid to the privacy and confidentiality of personal health information (69%)
Information about you collected by professional organizations and clubs (77%)	Males (73%) Females (81%) Younger Albertans (age 25-34) (70%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (81%) Little or no attention paid to the privacy and confidentiality of personal health information (67%) Heard of the HIA (80%) Not heard of the HIA (73%) Familiar with the OIPC (82%) Not familiar with the OIPC (76%)
Information about you collected by businesses when you contact them through the Internet (74%)	Middle-aged Albertans (age 45-54) (82%) Seniors (58%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (79%) Little or no attention paid to the privacy and confidentiality of personal health information (63%) Heard of the HIA (78%) Not heard of the HIA (71%) Familiar with the OIPC (80%) Not familiar with the OIPC (74%)
Information about your Internet and telephone usage collected by your employer while you are at work (66%)	Seniors (60%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (70%) Little or no attention paid to the privacy and confidentiality of personal health information (56%) Familiar with the OIPC (73%) Not familiar with the OIPC (65%) Satisfied with OIPC performance (72%) Dissatisfied with OIPC performance (67%)

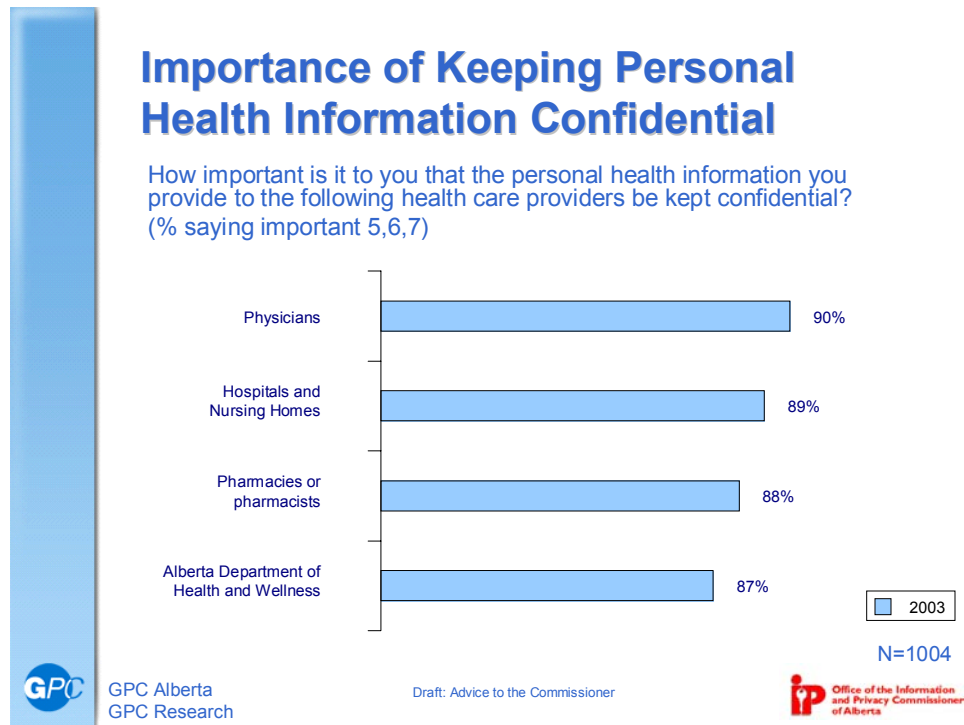
## 4.0 Views on Privacy and Confidentiality of Personal Health Information

Albertans pay a relatively high level of attention to their personal health care information. In fact, nearly three-quarters (71%) of respondents in the 2003 survey indicate that they personally pay attention to issues around the privacy and confidentiality of personal health information.

High levels of attention are more prevalent among females (75%) than males (68%), with Albertans between the ages of 45-65 (79%), those who heard about the HIA (79%), and those familiar with the OIPC (89%). Younger Albertans (age 18-34) (62%) pay less attention to issues around personal health information than the provincial average. There are also significant distinctions linked to levels of awareness – those who are aware of information protection laws (76%) versus those who are not aware (69%); those who have heard about the HIA (79%) versus those who have not heard about the HIA (64%); and those who are familiar with the OIPC (89%) versus those who are not familiar with the OIPC (68%).



Albertans attach considerable importance to the role of the health custodian in keeping their personal health information confidential. Physicians (90%), hospitals and nursing homes (89%), pharmacies or pharmacists (88%), and Alberta Health and Wellness (87%) are all considered to play important roles in keeping Albertans' personal health information, confidential.



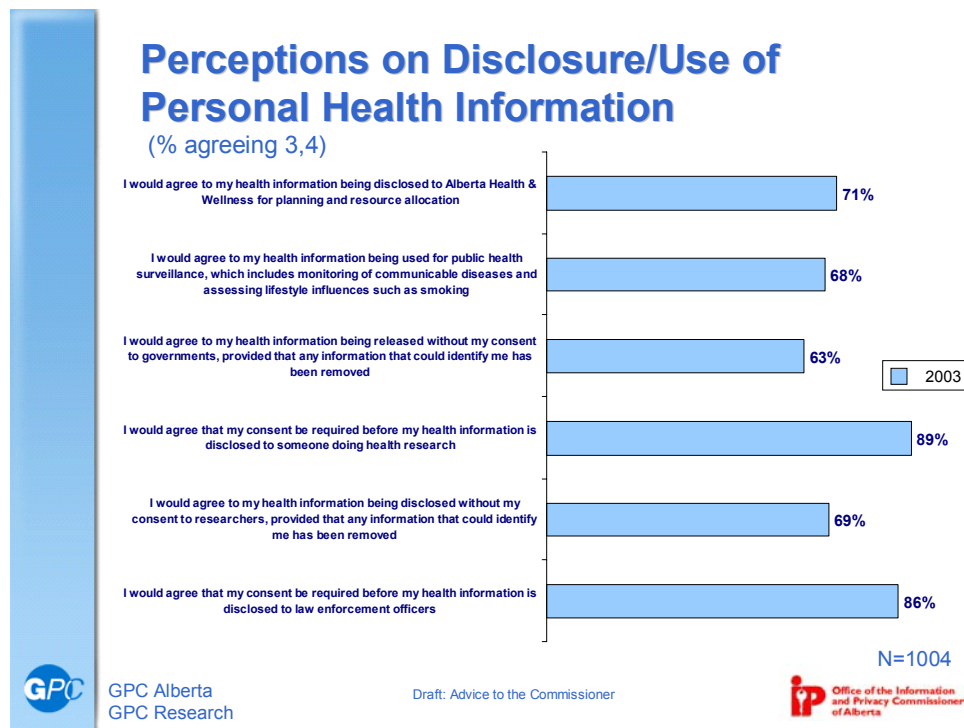
Of note, seniors seem to ascribe a slightly lower level of importance to all custodians: physicians (83%), pharmacies or pharmacists (84%), hospitals and nursing homes (82%), and Alberta Health and Wellness (82%). Not surprisingly, the level of importance ascribed to the various custodians is also driven by attention paid to the privacy and confidentiality of personal health information, as illustrated in the following table.

Health Custodian 2003	Overall rankings  % describing as important (5, 6, 7 on a 7- point scale)	Those paying some or a lot attention to the privacy and confidentiality of personal health information  % describing as important (5, 6, 7 on a 7-point scale)	Those paying little or no attention to the privacy and confidentiality of personal health information  % describing as important (5, 6, 7 on a 7-point scale)
Physicians	90	96	77
Hospital and nursing homes	89	94	74
Pharmacies or pharmacists	88	94	73
Alberta Health and Wellness	87	93	71

Albertans attach considerable importance to the exercise of individual consent when considering disclosure of their personal health information to custodians. Weaker levels of support are given to the disclosure of personal health information to custodians, without consent, even when there is some assurance that information that could identify the individual has been removed.

- I would agree that my consent be required before my health information is disclosed to someone doing health research (89%);
- I would agree that my consent be required before my health information is disclosed to law enforcement officers (86%);
- I would agree to my health information being disclosed to Alberta Health and Wellness for planning and resource allocation (71%);
- I would agree to my health information being disclosed without my consent to researchers, provided that any information that could identify me had been removed (69%);
- I would agree to my health information being used for public health surveillance, which includes monitoring of communicable diseases and assessing lifestyle influences such as smoking (68%); and

- I would agree to my health information being released without my consent to governments, provided that any information that could identify me has been removed (63%).



With respect to the disclosure of personal health information with consent to health researchers and law enforcement officers, seniors are less likely to be supportive than the provincial average, with levels of support of 80% and 81% respectively.

Levels of support for disclosure of personal information without consent to government and researchers are linked to attention paid to the privacy and confidentiality of personal health information. Those who pay little or no attention to the privacy and confidentiality of personal health information are more likely to be supportive of the disclosure of personal health records without consent, even when the identity of the individual is removed versus those who pay some or a lot of attention to the privacy and confidentiality of personal health information.

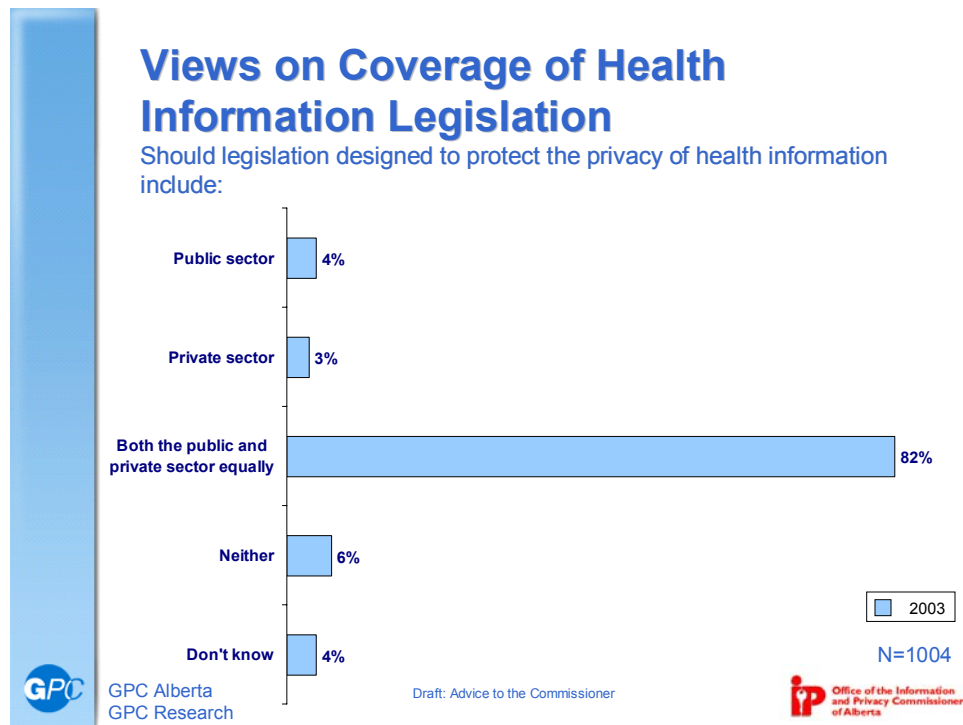


<b>Disclosure of personal health records without consent 2003</b>	<b>Overall rankings</b>  % agreeing (3,4)	<b>Those paying some or a lot attention to the privacy and confidentiality of personal health information</b>  % agreeing (3,4)	<b>Those paying little or no attention to the privacy and confidentiality of personal health information</b>  % agreeing (3,4)
I would agree to my health information being disclosed without my consent to researchers, provided that any information that could identify me has been removed	69	67	73
I would agree to my health information being released without my consent to governments, provided that any information that could identify me has been removed	63	62	68

Support for disclosure of personal health information, with or without consent, is positively correlated to the level of satisfaction with the performance of the OIPC, with the notable exception of health research. Those who are satisfied with the performance of the OIPC are more likely to support the disclosure of their personal health information, with or without consent.

Disclosure of Personal Health Information 2003	Overall rankings  % agreeing (3,4)	Satisfied with the performance of the OIPC  % agreeing (3,4)	Dissatisfied with the performance of the OIPC  % agreeing (3,4)
I would agree that my consent be required before my health information is disclosed to someone doing health research	89	87	88
I would agree that my consent be required before my health information is disclosed to law enforcement officers	86	90	80
I would agree to my health information being disclosed to Alberta Health and Wellness for planning and resource allocation	71	80	65
I would agree to my health information being disclosed without my consent to researchers, provided that any information that could identify me has been removed	69	75	65
I would agree to my health information being used for public health surveillance, which includes monitoring of communicable diseases and assessing lifestyle influences such as smoking	68	78	58
I would agree to my health information being released without my consent to governments, provided that any information that could identify me has been removed	63	74	56

Albertans clearly support legislation that protects the privacy of health information in both the public and private sector, equally (82%).

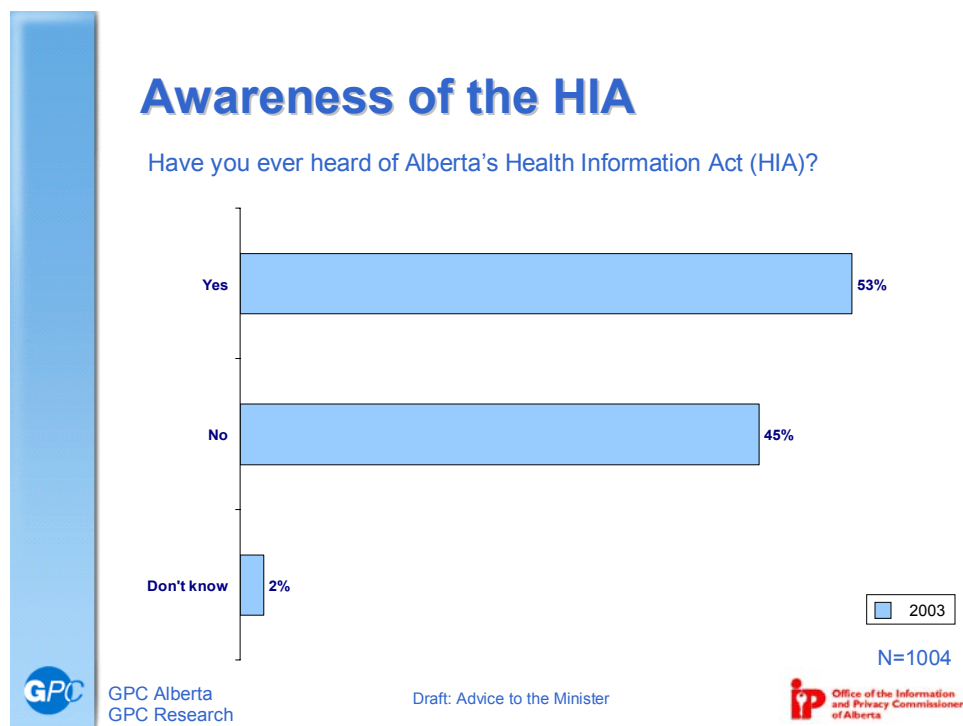


Support for the equal inclusion of both the public and private sectors is stronger among middle-aged Albertans (age 35-44) (88%) and those with a university education (89%). Weaker support is found among seniors (76%). There is some distinction in support between those who have heard about the HIA (85%) and those who had not heard of the Act (79%).

## 5.0 Alberta’s Health Information Act (HIA)

### 5.1 Awareness and Familiarity with the HIA

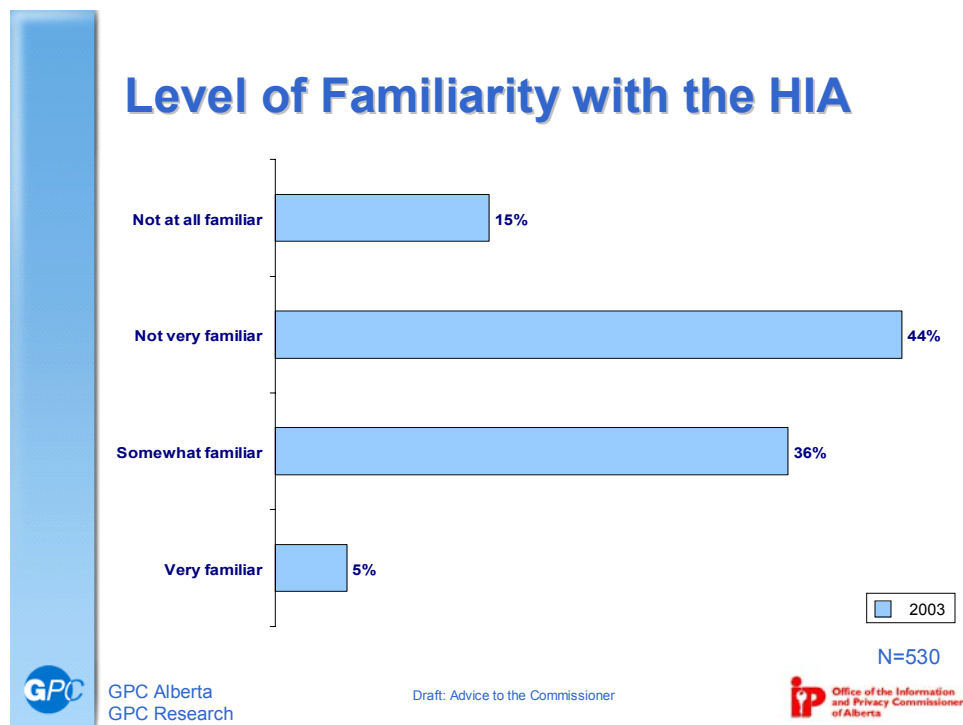
Over five-in-ten (53%) Albertans say they have heard about the HIA. Those Albertans who have a college or university education (58%-60%) are more apt to say that they have heard of the HIA than younger Albertans (age 18-35) (41%-42%) and those with an education of high school or less (43%).



Awareness of the HIA is also linked to attention paid to the privacy and confidentiality of personal health information and the level of familiarity and satisfaction with the OIPC. Those who have paid some or lot of attention to the privacy and confidentiality of personal health information (58%), those familiar with the OIPC (66%), and satisfied with OIPC performance (57%) are more likely to have heard of the HIA than those who pay little or no attention to the privacy and confidentiality of personal health information (40%), those not familiar with the OIPC (50%), and those dissatisfied with OIPC performance (49%).

Just 41% of those Albertans who have heard about the HIA say are familiar with it, indicating a relatively low level of knowledge of the scope and content of the Act, or very little experience in having to use the Act to access their personal health information.

Familiarity is stronger among females (45%) than males (35%), among those who are familiar with information protection laws (49%) than those who are not (34%), those who pay some or lot of attention to the privacy and confidentiality of personal health information (46%) than those who pay little or no attention (22%), those who are familiar with the OIPC (73%) versus those who are not (32%) and those who are satisfied with OIPC performance (55%) versus those who are dissatisfied (37%). Seniors exhibit a low level of familiarity with the HIA at just 33%.

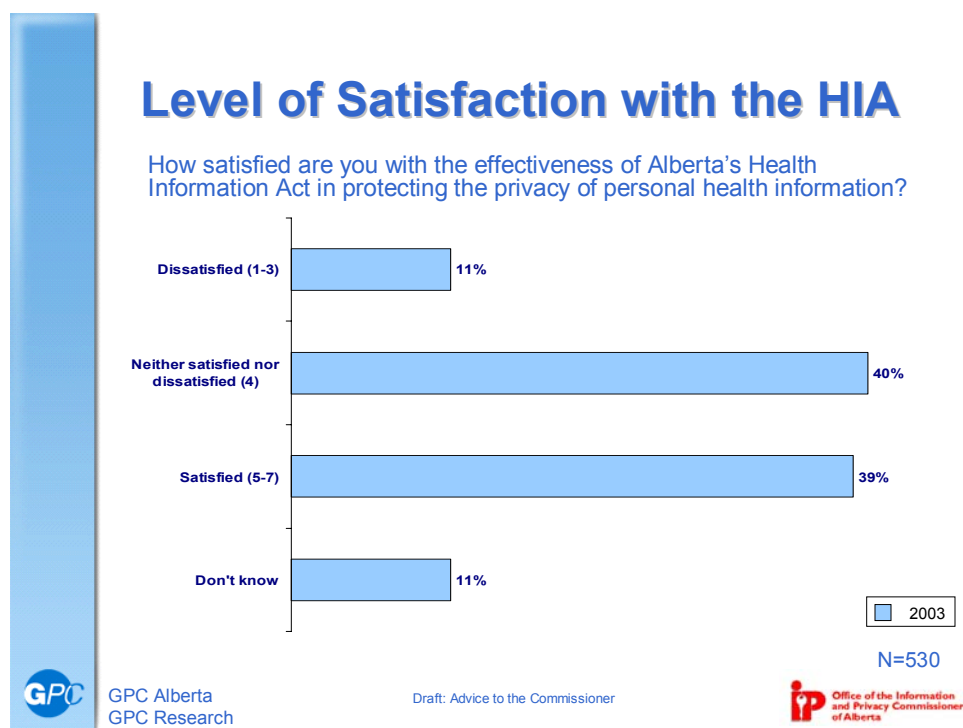


## 5.2 Satisfaction with the HIA

Most Albertans who have heard about the HIA give it high marks. Of those who have heard about the HIA, nearly four-in-ten (39%) are satisfied with the effectiveness of the HIA in protecting the privacy of personal health information, while just 11% are dissatisfied.

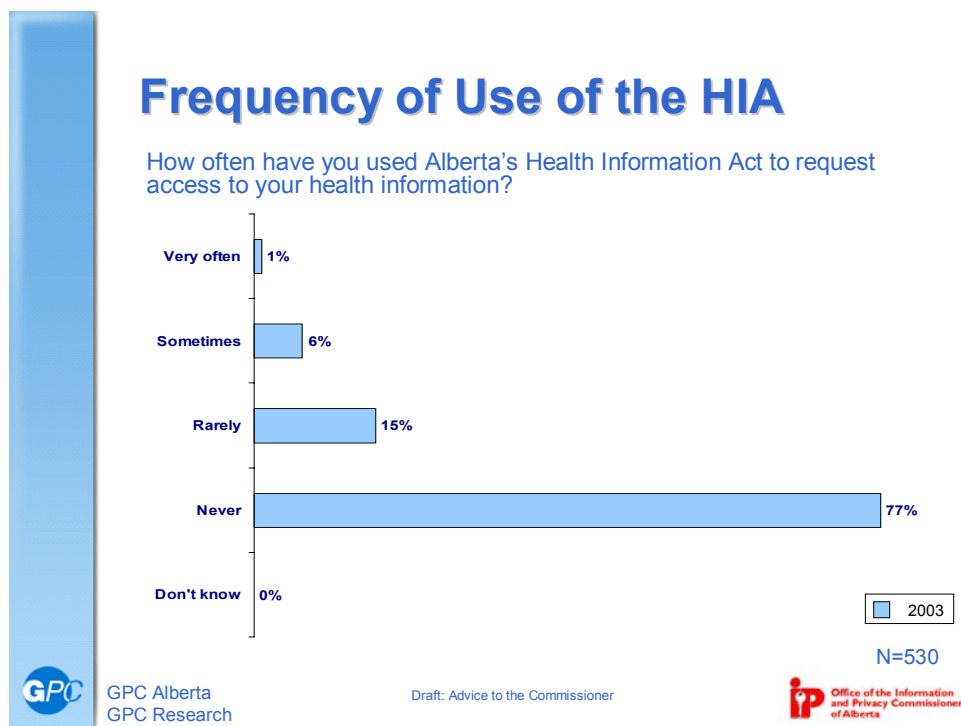
Four-in-ten (40%) of those who have heard about the Act are neither satisfied nor dissatisfied. This could indicate either a lack of familiarity with the content and scope of the Act, or not having to use the Act to access personal health information due to the willingness of their health providers to readily provide the requested information.

Satisfaction with the effectiveness of the Act is stronger among younger Albertans (age 18-34) (45%-53%) than among older Albertans (45+) (32%-41%), and those satisfied with the performance of the OIPC (69%) versus those who are dissatisfied (22%).



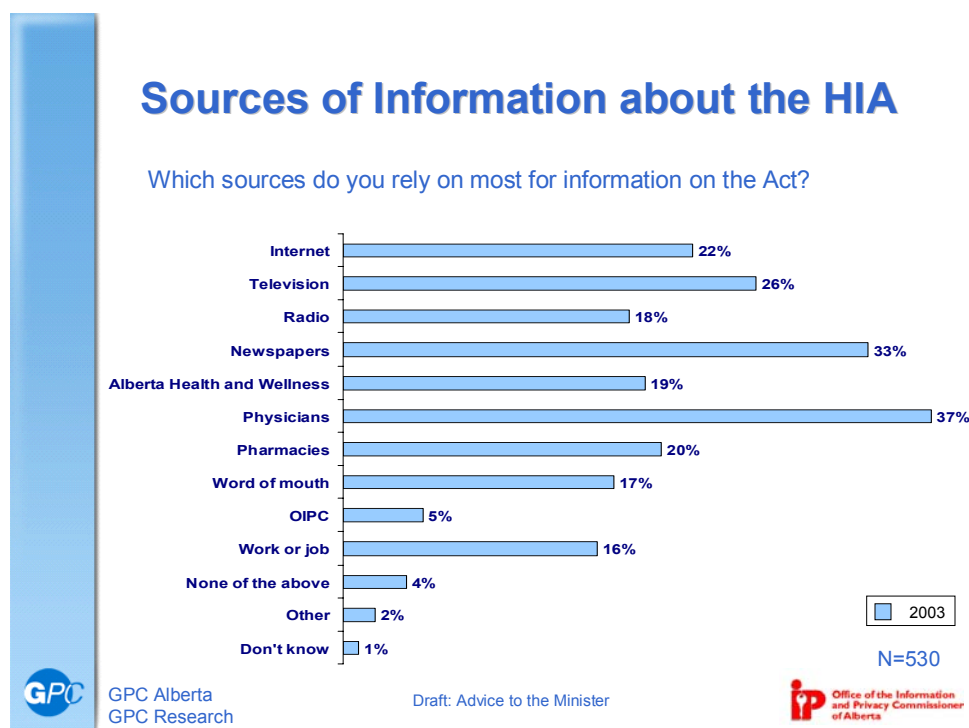
### 5.3 Use of the HIA

The public's use of the HIA is extremely limited, even among those who have indicated that they have heard of the Act. Only 22% of respondents who are aware of the HIA have used the Act to access their personal health information. The low frequency of use of the Act may be explained by the willingness of health providers to readily provide requested information to their patients.



## 5.4 Sources of Information about the HIA

Albertans rely on a variety of information sources about the HIA. Physicians (37%) and newspapers (33%) are the primary sources of information. A second tier of communications vehicles –television (26%), Internet (22%), pharmacies (20%), Alberta Health and Wellness (19%), radio (18%), word of mouth (17%), and work or job (16%) – are relied upon less frequently. Specialized communications sources, such as the OIPC (5%), are cited infrequently as sources of information about the Act.



Seniors tend to rely more frequently on such information sources as physicians (44%), newspapers (40%), television (26%), radio (26%), and Alberta Health and Wellness (26%) than the provincial average.

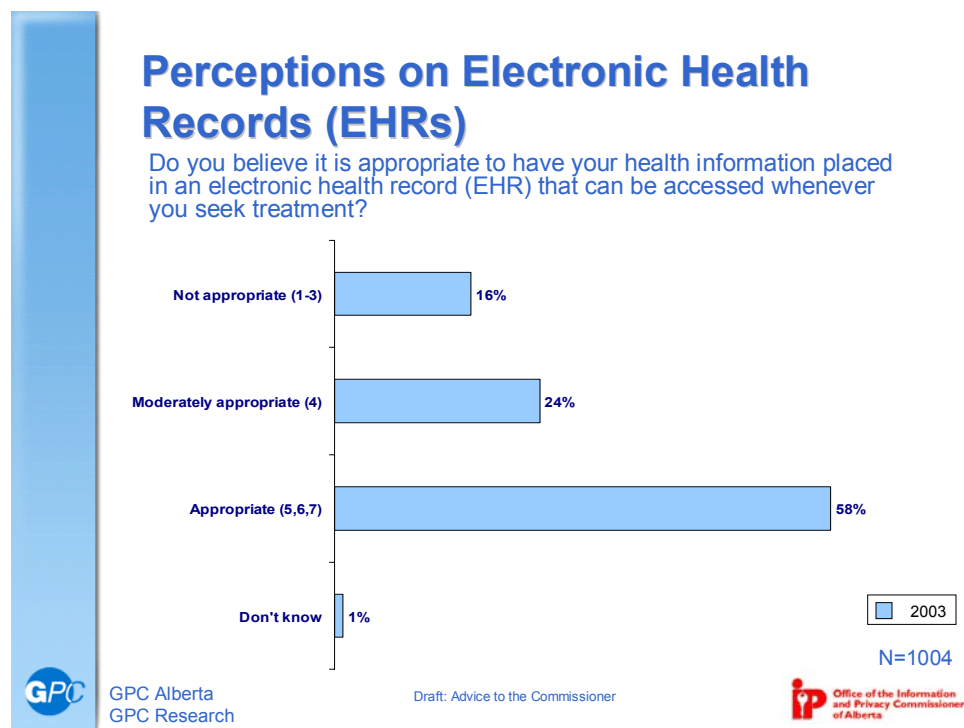
Reliance on the OIPC as a source of information about the Act (5%) is generally consistent across demographic and attitudinal variables, with the notable exception of those who are familiar with the OIPC (14%).



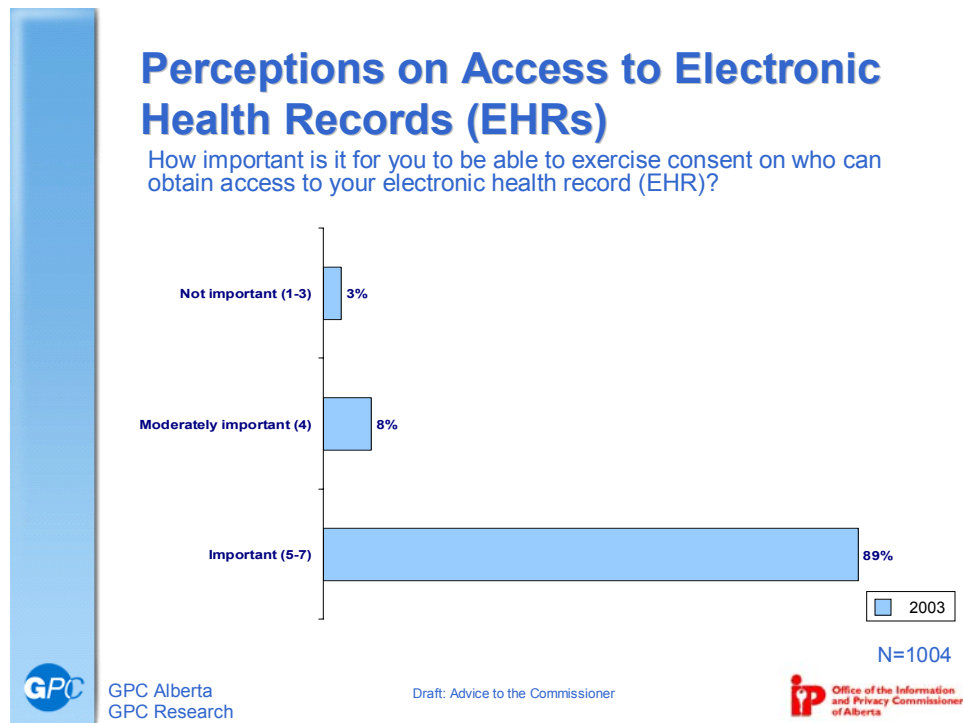
## 6.0 Electronic Health Records (EHRs)

Albertans are strong supporters of having personal health information placed in an electronic health record (EHR) that can be accessed at time of treatment. Over eight-in-ten Albertans (82%) believe it is moderate to very appropriate to have personal health information placed in an EHR that can be accessed whenever treatment is sought by an individual. Fifty-eight per cent of respondents believe it is appropriate to very appropriate. Just 16% of Albertans believe that use of an EHR in treatment is an inappropriate use of personal health information.

Appropriate to very appropriate responses were most prevalent among younger Albertans (age 18-34) (63%-64%) and those satisfied with OIPC performance (75%).

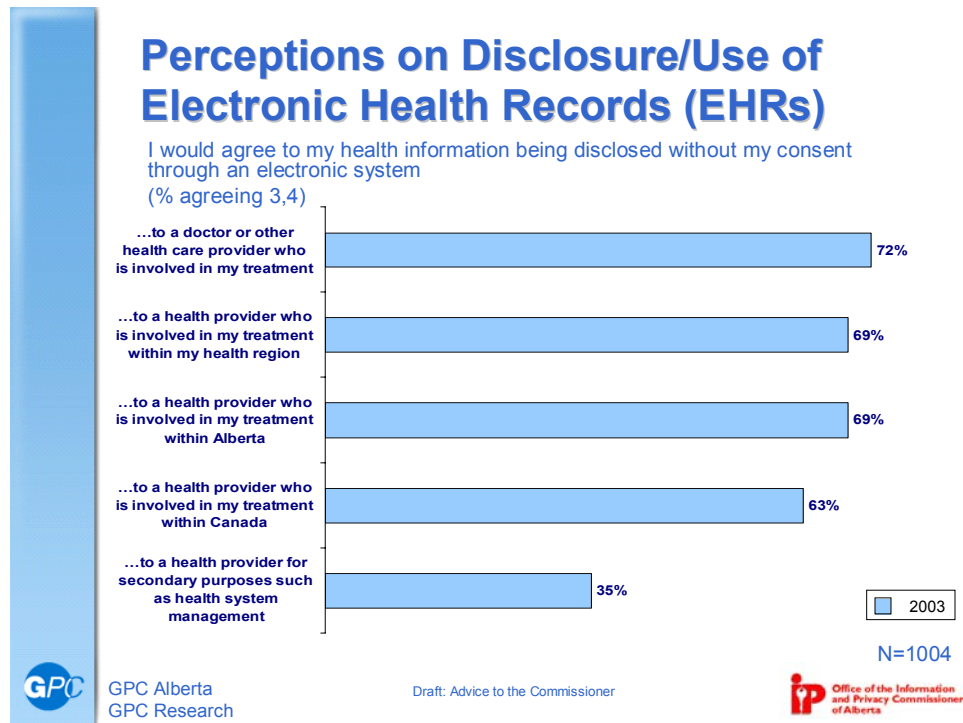


The exercise of individual consent on who can obtain access to an EHR is considered extremely important to Albertans. 89% of respondents believe it is important for an individual to be able to exercise consent on who can obtain access to their EHR.



Albertans were asked a series of statements as to their level of support for the disclosure of personal health information, without consent, through an EHR, to health providers for various purposes. The data reveals that support for the disclosure of EHRs, without consent, is linked to the relationship with and proximity to the health provider.

- Doctor or other health care provider involved in my treatment (72% agree)
- Health care provider involved in my treatment within Alberta (69% agree)
- Health care provider involved in my treatment within my health region (69% agree)
- Health care provider involved in my treatment within Canada (63% agree)
- Health care provider for secondary purposes such as health system management (35% agree)



The following table highlights the demographic and attitudinal variations regarding agreement to the disclosure of health information through an electronic system, without consent, to health providers for various purposes. The focus is on those groups that tend to express higher or lower than average levels of agreement, and where significant distinctions in agreement arise.

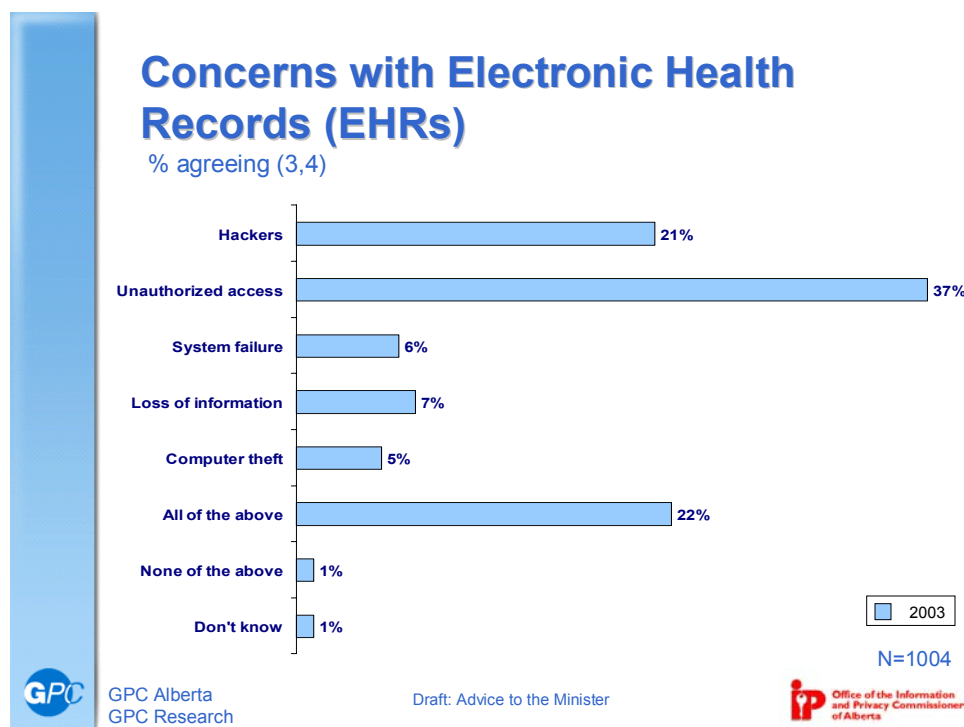
<i>I would agree to my health information being disclosed without my consent through an electronic system...</i>	<b>Demographic and attitudinal variations % agreeing (3.4)</b>
Doctor or other health care provider involved in my treatment (72% agree)	Males (76%) versus females (70%) Albertans (age 25-34) (78%) Albertans (age 55-64) (64%) Urban (71%) versus rural (75%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (71%) Little or no attention paid to the privacy and confidentiality of personal health information (77%) Those satisfied with OIPC performance (88%) Those dissatisfied with OIPC performance (63%)
Health care provider involved in my treatment within Alberta (69% agree)	Albertans (age 55-64) (62%) Seniors (73%) Self-employed Albertans (63%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (67%) Little or no attention paid to the privacy and confidentiality of personal health information (73%) Those satisfied with OIPC performance (81%) Those dissatisfied with OIPC performance (55%)
Health care provider involved in my treatment within my health region (69% agree)	Males (72%) versus females (66%) Albertans (age 55-64) (60%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (66%) Little or no attention paid to the privacy and confidentiality of personal health information (76%) Those satisfied with OIPC performance (81%) Those dissatisfied with OIPC performance (58%)
Health care provider involved in my treatment within Canada (63% agree)	Males (67%) versus females (60%) Older Albertans (age 55-64) (52%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (60%) Little or no attention paid to the privacy and confidentiality of personal health information (70%) Those satisfied with OIPC performance (75%) Those dissatisfied with OIPC performance (55%)
Health care provider for secondary purposes such as health system management (35% agree)	Males (38%) versus females (33%) Albertans (age 35-44) (42%) Albertans (age 55-64) (28%) Some or a lot of attention paid to the privacy and confidentiality of personal health information (32%) Little or no attention paid to the privacy and confidentiality of personal health information (44%) Those satisfied with OIPC performance (48%) Those dissatisfied with OIPC performance (26%)

Albertans were asked to rank a list of concerns relating to the existence of EHRs. Unauthorized access to EHRs was the highest concern mentioned by Albertans at 37%. This was followed by a second tier of concerns – hackers (21%). Lower level of concerns were those dealing with a loss of information (7%), system failure (6%), and computer theft (5%). Twenty-two per cent of respondents mentioned all of the above concerns.

Among those citing unauthorized access (37%), the university educated (45%) and those who have heard about the HIA (41%) made more frequent mention of this as their top concern. There was less frequent mention of this concern made by seniors (33%) and those who pay little or no attention to the privacy and confidentiality of personal health information (32%).

Among those citing hackers (21%) as a concern, more frequent mention was made by younger Albertans (age 25-34) (28%), those who pay little or no attention to the privacy and confidentiality of personal health information (26%), and those with little or no awareness of the HIA (25%). Less mention than the provincial average was made by seniors (15%) and those who have heard of the HIA (17%).

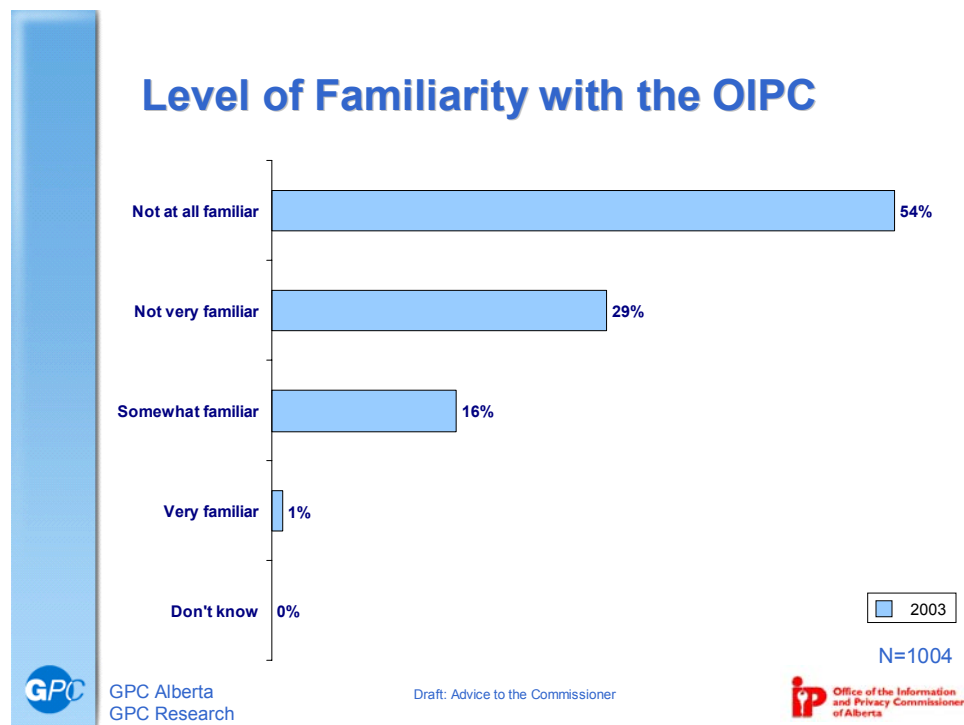
For those who cited all of the above concerns (22%), more frequent mention was made by older Albertans (age 45-54) (29%) and those dissatisfied with OIPC performance (27%).



## 7.0 Office of the Information and Privacy Commissioner (OIPC)

### 7.1 Familiarity with the OIPC

Public familiarity with OIPC is low. Just 17% of respondents are somewhat or very familiar with the OIPC, while 83% are not at all or not very familiar. The low level of familiarity may be explained by the low frequency of use of personal privacy legislation by Albertans.



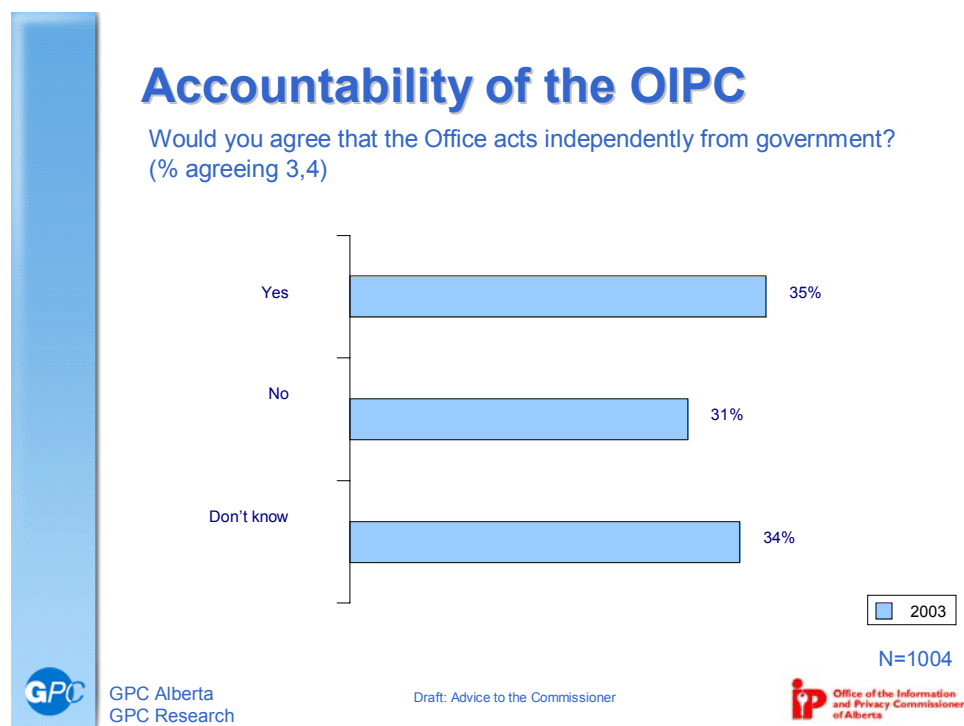
Familiarity with the OIPC is higher among older Albertans (age 45-64) (23%-26%) and those with a university education (25%). Familiarity is very weak among younger Albertans (age 18-34) (9%-11%).

There are significant distinctions in familiarity with the OIPC on a number of the attitudinal variables. Those who are aware of information protection laws (27%) are much more familiar with the OIPC than those who are not aware of those laws (11%). Those who pay some or a lot of attention to the privacy and confidentiality of personal health information (21%) are also more familiar with the OIPC than those who pay little or no attention (7%). Those who have heard about the HIA (21%) are more likely to be familiar with the OIPC than those who have not heard about the OIPC (12%). This seems to suggest that familiarity with the OIPC is driven by the knowledge of and frequency of use of personal privacy legislation by Albertans.

## **7.2 OIPC Accountability**

There is a mixed assessment among Albertans as to whether the OIPC operates independently from government, indicating a relatively low level of experience in dealing with the Office or some uncertainty in the public mind as to the mandate and goals of the organization.

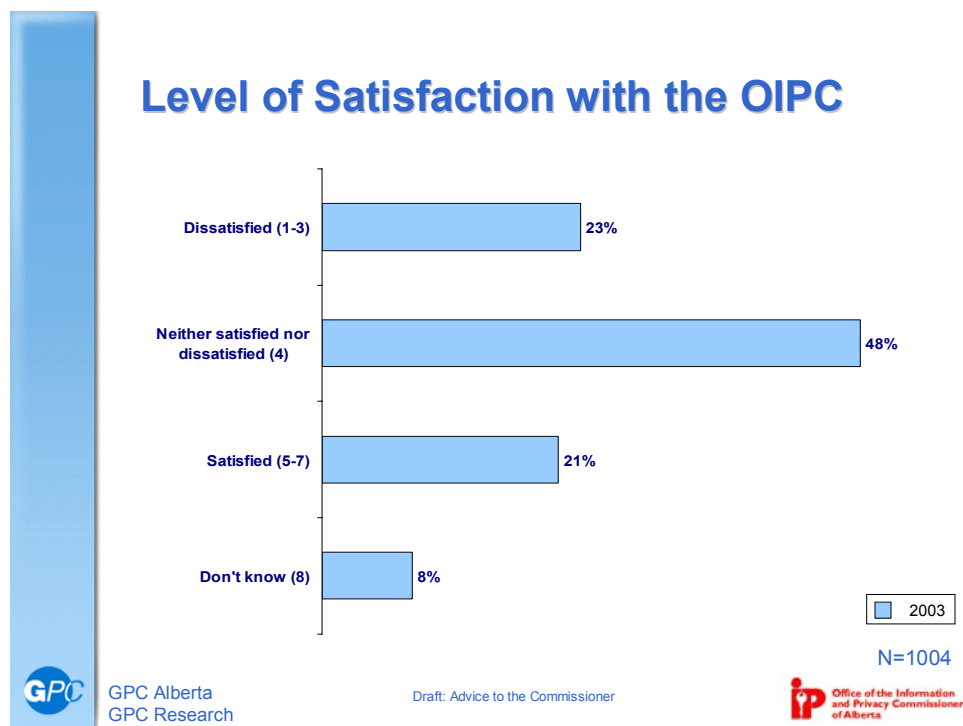
Thirty-five per cent of respondents believe that the OIPC operates independently from government, while 31% of respondents believe that the organization is not arms-length from government. There are a significant number of Albertans (34%) who are unable to express an opinion, suggesting a low level of involvement with the Office or an unfamiliarity regarding the OIPC's role and functions.



Attitudes of the independence of the OIPC are linked to the level of familiarity and satisfaction with the organization. Those familiar with the OIPC are marginally more likely to believe that the Office operates independently from government (43%) than those who are unfamiliar (38%). Those who are satisfied with OIPC performance are more apt to ascribe independence to the organization (56%) than those who are dissatisfied (22%). Females (38%) rather than males (28%), rural (37%) rather than urban (31%) residents, and those who pay little or no attention to the privacy and confidentiality of personal health information (41%) are much more likely not to express an opinion on OIPC independence.

### 7.3 Satisfaction with the OIPC

Overall levels of satisfaction with the performance of the OIPC are mixed at 21%, while the level of dissatisfaction is 23%. The mandate and mission of the organization is either not well understood by Albertans, or there is little involvement by the public with the Office, as 48% of respondents are neither satisfied nor dissatisfied with the OIPC.

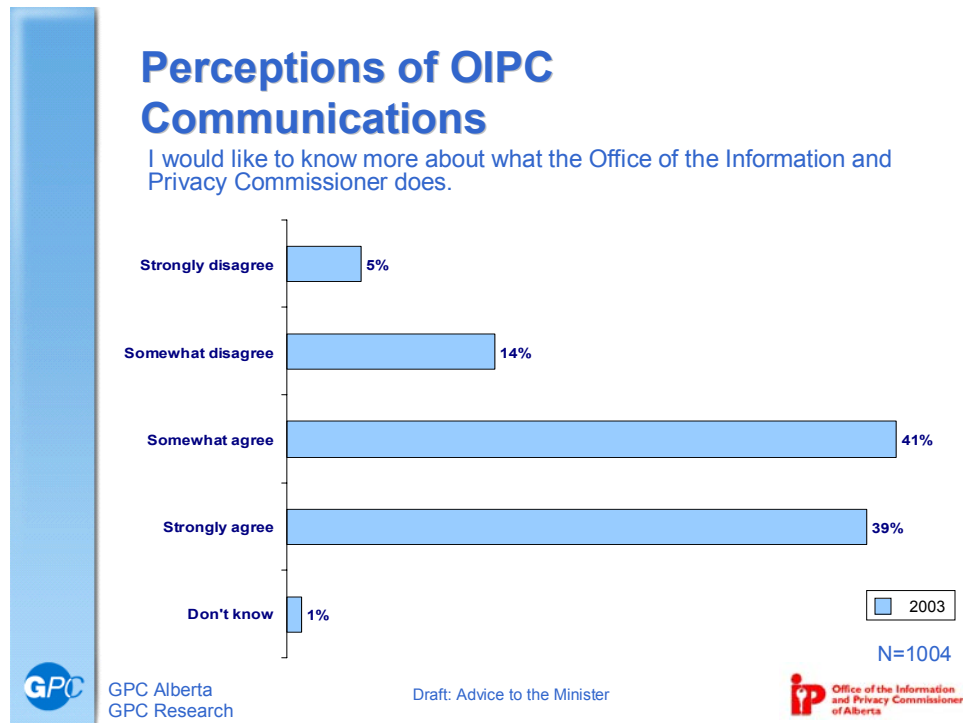


Satisfaction/dissatisfaction with the performance of the OIPC is marginally driven by the level of familiarity with the organization. Among those who are familiar with the organization, 28% are satisfied by the OIPC’s performance versus 27% who are dissatisfied. However, even among those familiar with the OIPC, 41% are neither satisfied nor dissatisfied. Middle-aged Albertans (age 45-54) have a more unfavourable view of the organization than the provincial average (16% satisfied and 29% dissatisfied). Of note, younger Albertans (age 25-34) (59%) are more likely to be neither satisfied nor dissatisfied with the OIPC performance than the provincial average.



## 7.4 Perceptions of OIPC Communications

Despite relatively low levels of familiarity and satisfaction with the OIPC, there is a very strong expressed public desire to hear more about what the organization does. Nearly eight-in-ten Albertans (79%) want to know more about what the organization does.



There is some indication in the data that proactive strategies on the part of the OIPC may be useful in driving up levels of familiarity and satisfaction with the organization.

For example, among those who want to know more about the OIPC does, it is those who are not familiar with the organization (80%) and those dissatisfied with the organization's performance (81%) who express a strong desire to learn more about the Office's activities.

<b>Respondents wanting to know about what the OIPC does 2003</b>	<b>Overall rankings</b>  % agreeing (3,4)	<b>Unfamiliar with the OIPC</b>  % agreeing (3,4)	<b>Dissatisfied with the performance of the OIPC</b>  % agreeing (3,4)
I would like to know more about what the OIPC does	79	80	81

## 8.0 Conclusions

Since the completion of our initial survey in August 2000, and with the explosive proliferation of electronic technology, Albertan's concern about the privacy of personal information has grown. Respondents to the 2003 OIPC survey attach a great deal of importance to the protection of personal privacy, and there is broad support for legislative initiatives to regulate the use of personal information in both the public and private sector.

This is particularly the case with the protection and use of sensitive information, such as the personal health records. The use of electronic health records (EHRs) to collect and store personal health information receives relatively strong support, but there is an undercurrent of concern among Albertans about potential breaches to privacy through such means as unauthorized access and hackers.

Albertans attach a great deal of importance to the role of health custodians, particularly those in which they have a personal trust relationship, in keeping personal health information, including EHRs, confidential. Respondents to the 2003 survey want some measure of personal control, through the exercise of consent, over the disclosure of such information by custodians.

Despite broad support for laws to protect the privacy and confidentiality of personal health information, it is clear that awareness and understanding of existing initiatives in the area, such as Alberta's Health Information Act (HIA), are rather limited. This affects levels of familiarity and satisfaction with both the HIA and the OIPC.

Lack of awareness and understanding may be due to the lack of experience in having to use the Act and/or perhaps a manifestation of the willingness of custodians to readily provide such information on request. It may also be a result of the trust relationship between Albertans and their health care custodians – physicians, hospitals and nursing homes, pharmacies/pharmacists and Alberta Health and Wellness. This is an area that will need to be explored in future surveys. What is clear is that use of the HIA by individuals to access their own personal health information, even among those aware of the Act's application, is extremely limited.

Lack of familiarity with the substance of the HIA has a great deal of influence on perceptions of its effectiveness. While there is general satisfaction with the effectiveness of the Act among those who have some familiarity, many Albertans simply do not have enough information at hand to register an opinion at all.

The OIPC's role in managing the HIA is not well understood by Albertans, perhaps due to the fact that lack of experience in having to use the HIA means public involvement with the Office is limited. In fact, less than two-in-ten Albertans are familiar with the OIPC and a significant number of survey respondents believe the Office serves the interests of government rather than the public. Low levels of familiarity with the OIPC affect public satisfaction with the performance of the organization.

In sum, it is clear from our analysis of the 2003 survey data that there is a dichotomy between the importance that Albertans place on the protection and use of personal health information, growing public concern over the privacy of personal information, and the level of public awareness and understanding of the HIA.

As the body that oversees the access and privacy provisions of the HIA, the OIPC can play a key role in bridging the gap between the importance attached to the protection of personal health information and awareness and understanding of the Act. There is a positive correlation between levels of awareness and support for the HIA and awareness satisfaction with OIPC performance. In other words, as Albertans become more familiar with the role and mandate of the OIPC, they tend to increase their level of awareness and understanding of the HIA. Higher awareness of the HIA leads to higher levels of satisfaction with the effectiveness of the Act.

"Bridging the gap" is best accomplished through the OIPC being more proactive in educating Albertans about the purpose of the HIA, and the operation of the Office itself. Given Albertans interest in issues around health information, they would clearly be receptive to increased communications about the HIA, emanating from the OIPC itself. In fact, nearly eight-in-ten Albertans want to know more about the OIPC, representing a strategic lever to drive up levels of familiarity and satisfaction with the organization, and by extension the HIA.

The challenge for the OIPC over the next year is to effectively communicate the role and mandate of the organization, including the administration of the HIA, through traditional communication vehicles upon which Albertans rely for health information (i.e. physicians, newspapers, television and radio). Distribution of OIPC materials on the HIA should be targeted towards those communications vehicles that would derive maximum exposure and attention. In this respect, the OIPC would also be well served in implementing strategies that actively engage the media as a means of raising levels of awareness, understanding and satisfaction with the HIA, and the performance of the organization in administering the Act.

GPC understands that the OIPC Commissioner is active in speaking engagements at various events throughout the province in which media are present. We encourage a continuation and expansion of these efforts. GPC also recommends that the high credibility and respect of the Commissioner be utilized more effectively through regular editorial board meetings, as well as media briefings on important issues pertaining to the HIA as they arise.

Finally, GPC proposes that evaluation of the effectiveness of communications efforts by OIPC to raise awareness and understanding of the HIA, and the role of the Office in administering the Act, be best conducted through a follow-up survey. GPC believes that the 2003 survey establishes a benchmark of Albertans' view regarding personal health information, and a baseline for comparison in future years.

## 9.0 Next Steps

The protection of individual privacy and the collection, use and disclosure of personal information by the public and private sectors will continue to evolve in response to the proliferation of new technologies. In particular, the advent of electronic records to collect financial and health information, and the utilization of these records by public and private sector custodians, promises to change the face of personal privacy over the next few years.

The 2003 OIPC survey has drawn some important conclusions from the views and attitudes held by Albertans around such issues as individual privacy, the protection and use of sensitive personal information, EHRs, the HIA, and the role of the OIPC. Nevertheless, resource and time constraints affecting the length of the 2003 questionnaire and the rapid changes taking place within the privacy field, have admittedly limited the scope of observation and analysis.

Through an assessment of the 2003 findings, the following areas have been identified as requiring further exploration in subsequent surveys:

- The link between support for the exercise of individual consent regarding disclosure/use of personal health information and the relationship with and level of trust in custodians;
- The link between awareness, understanding, use and support of the HIA and the OIPC and the readiness of custodians to provide access to personal information to individuals without resort to the legislative and regulatory framework;
- The nature of the relationship and the level of trust in the role of the custodian involved in the protection, collection, use and disclosure of personal information;
- Views and attitudes of Albertans towards the disclosure/use of personal health records by health providers for treatment purposes;
- Views and attitudes of Albertans familiar with the OIPC regarding the independence and accountability of the organization;
- Levels of awareness, understanding and use of the HIA and EHRs by custodians as defined under the Act;
- Views and attitudes of Albertans regarding the collection, use and disclosure of personal information by private sector organizations in Alberta, i.e. Personal Information Protection Act; and

- Views and attitudes of Albertans towards new developments in the field of personal health information.

## Appendix A: Weighted Marginals



**SEX:**

DO NOT READ Note Gender of Respondent

N = .....	1004	100%
Male.....1	446	44%
Female.....2	558	56%

**Q1:**

As you may or may not know, there has been considerable discussion about information privacy; that is the means by which governments, businesses and other organizations use and protect information they collect about you. I'm going to read you a series of statements and for each, I'd like you tell me whether you strongly agree, somewhat agree, somewhat disagree or strongly disagree with the statement.

N = .....	1004	100%
Press Enter or hit OK to Continue .....1	1004	100%

**Q1A:**

It is important to protect individual privacy in a democracy like Alberta

N = .....	1004	100%
Strongly Disagree .....1	10	1%
Somewhat Disagree .....2	8	1%
Somewhat Agree.....3	139	14%
Strongly Agree .....4	842	84%
Don't know/ Refused.....9	5	0%

**Q1B:**

I am concerned that the privacy of personal information is at risk in Alberta

N = .....	1004	100%
Strongly Disagree .....1	43	4%
Somewhat Disagree .....2	166	17%
Somewhat Agree.....3	397	40%
Strongly Agree .....4	342	34%
Don't know/ Refused.....9	56	6%

**Q1C:**

I am concerned about the privacy of my own personal information

N = .....	1004	100%
Strongly Disagree .....1	48	5%
Somewhat Disagree .....2	124	12%
Somewhat Agree.....3	336	33%
Strongly Agree .....4	488	49%
Don't know/ Refused.....9	8	1%

**Q1D:**

I am more concerned about the privacy of my own personal information than I was five years ago

N = .....	1004	100%
Strongly Disagree .....	59	6%
Somewhat Disagree .....	111	11%
Somewhat Agree.....	221	22%
Strongly Agree .....	608	61%
Don't know/ Refused.....	5	0%

**Q2:**

For each of the following statements, I would like you to tell me, using a 7 point scale where 1 is not important at all and 7 is very important, how important it is to keep each of the following private and safe.

N = .....	1004	100%
Press Enter or hit OK to Continue .....	1004	100%

**Q2A:**

Your own personal health care records

N = .....	1004	100%
1 - Not important at all.....	29	3%
2.....	15	1%
3.....	16	2%
4 - Moderately important.....	44	4%
5.....	94	9%
6.....	121	12%
7 - Very important .....	685	68%
Don't know/ Refused.....	0	0%

**Q2B:**

Your E-mail messages on the Internet

N = .....	1004	100%
1 - Not important at all.....	30	3%
2.....	10	1%
3.....	27	3%
4 - Moderately important.....	62	6%
5.....	118	12%
6.....	120	12%
7 - Very important .....	556	55%
Don't know/ Refused.....	81	8%

**Q2C:**

Your shopping information over the Internet

N = .....	1004	100%
1 - Not important at all.....1	70	7%
2.....2	33	3%
3.....3	38	4%
4 - Moderately important.....4	73	7%
5.....5	169	17%
6.....6	111	11%
7 - Very important .....7	414	41%
Don't know/ Refused.....9	96	10%

**Q2D:**

Your Internet surfing history

N = .....	1004	100%
1 - Not important at all.....1	57	6%
2.....2	32	3%
3.....3	45	4%
4 - Moderately important.....4	97	10%
5.....5	176	18%
6.....6	103	10%
7 - Very important .....7	398	40%
Don't know/ Refused.....9	96	10%

**Q2E:**

Accounts in your financial institution

N = .....	1004	100%
1 - Not important at all.....1	6	1%
2.....2	2	0%
3.....3	7	1%
4 - Moderately important.....4	16	2%
5.....5	35	3%
6.....6	61	6%
7 - Very important .....7	875	87%
Don't know/ Refused.....9	2	0%

**Q2F:**

Your credit card numbers

N = .....	1004	100%
1 - Not important at all.....1	6	1%
2.....2	4	0%
3.....3	1	0%
4 - Moderately important.....4	6	1%
5.....5	8	1%
6.....6	32	3%
7 - Very important .....7	939	94%
Don't know/ Refused.....9	8	1%

**Q2G:**

Information about your donations to charities

N = .....	1004	100%
1 - Not important at all.....1	80	8%
2.....2	51	5%
3.....3	67	7%
4 - Moderately important.....4	143	14%
5.....5	243	24%
6.....6	124	12%
7 - Very important .....7	289	29%
Don't know/ Refused.....9	7	1%

**Q2H:**

Your utility bills, such as telephone, cable, gas, or electricity

N = .....	1004	100%
1 - Not important at all.....1	71	7%
2.....2	51	5%
3.....3	68	7%
4 - Moderately important.....4	160	16%
5.....5	265	26%
6.....6	134	13%
7 - Very important .....7	250	25%
Don't know/ Refused.....9	5	0%

**Q2I:**

Your information held in credit reports

N = .....	1004	100%
1 - Not important at all.....1	14	1%
2.....2	7	1%
3.....3	14	1%
4 - Moderately important.....4	31	3%
5.....5	78	8%
6.....6	98	10%
7 - Very important .....7	752	75%
Don't know/ Refused.....9	10	1%

**Q2J:**

Your information about receiving government benefits, such as social assistance or Workers Compensation payments

N = .....	1004	100%
1 - Not important at all.....1	38	4%
2.....2	25	2%
3.....3	30	3%
4 - Moderately important.....4	72	7%
5.....5	176	18%
6.....6	152	15%
7 - Very important .....7	497	50%
Don't know/ Refused.....9	14	1%



**Q2K:**

Information you provide to government registries, such as the motor vehicle registry

N = .....		1004	100%
1 - Not important at all.....	1	31	3%
2.....	2	19	2%
3.....	3	39	4%
4 - Moderately important.....	4	93	9%
5.....	5	165	16%
6.....	6	155	15%
7 - Very important .....	7	494	49%
Don't know/ Refused.....	9	8	1%

**Q3:**

Using a 7 point scale where 1 is not important at all and 7 is very important, how important is it to have legislation in Alberta to regulate the private sector's use of personal information?

N = .....		1004	100%
1 - Not important at all.....	1	13	1%
2.....	2	4	0%
3.....	3	9	1%
4 - Moderately important.....	4	44	4%
5.....	5	129	13%
6.....	6	186	19%
7 - Very important .....	7	614	61%
Don't know/ Refused.....	9	5	0%

**Q4:**

I would like you to tell me; again using a 7 point scale where 1 is not important at all and 7 is very important, how important is it to you to have such legislation include the following:

N = .....		1004	100%
Press Enter or hit OK to Continue .....	1	1004	100%

**Q4A:**

Information about you collected by your employer

N = .....		1004	100%
1 - Not important at all.....	1	24	2%
2.....	2	14	1%
3.....	3	19	2%
4 - Moderately important.....	4	60	6%
5.....	5	145	14%
6.....	6	147	15%
7 - Very important .....	7	561	56%
Don't know/ Refused.....	9	34	3%

**Q4B:**

Information about you as a customer collected by businesses

N = .....	1004	100%
1 - Not important at all.....1	33	3%
2.....2	19	2%
3.....3	37	4%
4 - Moderately important.....4	96	10%
5.....5	215	21%
6.....6	160	16%
7 - Very important .....7	439	44%
Don't know/ Refused.....9	5	0%

**Q4C:**

Information about you as a member collected by professional organizations or clubs

N = .....	1004	100%
1 - Not important at all.....1	30	3%
2.....2	18	2%
3.....3	45	4%
4 - Moderately important.....4	116	12%
5.....5	223	22%
6.....6	152	15%
7 - Very important .....7	401	40%
Don't know/ Refused.....9	19	2%

**Q4D:**

Information about you collected by your financial institution

N = .....	1004	100%
1 - Not important at all.....1	14	1%
2.....2	6	1%
3.....3	9	1%
4 - Moderately important.....4	40	4%
5.....5	98	10%
6.....6	103	10%
7 - Very important .....7	726	72%
Don't know/ Refused.....9	8	1%

**Q4E:**

Information about you collected by businesses when you contact them through the Internet

N = .....	1004	100%
1 - Not important at all.....1	38	4%
2.....2	17	2%
3.....3	40	4%
4 - Moderately important.....4	84	8%
5.....5	163	16%
6.....6	134	13%
7 - Very important .....7	454	45%
Don't know/ Refused.....9	74	7%

**Q4F:**

Information about your Internet and telephone usage collected by your employer while you are at work

N = .....	1004	100%
1 - Not important at all.....1	72	7%
2.....2	43	4%
3.....3	49	5%
4 - Moderately important.....4	114	11%
5.....5	177	18%
6.....6	121	12%
7 - Very important .....7	366	36%
Don't know/ Refused.....9	62	6%

**Q5:**

Are you aware of any laws which are intended to protect your personal information?

N = .....	1004	100%
Yes.....1	386	38%
No.....2	605	60%
Don't know/ Refused.....9	13	1%

**Q6:**

Which laws have you heard about? [DO NOT READ LIST]

=&gt; +1

si NOT Q5=1

N = .....	386	100%
Alberta's Freedom of Information and Protection of Privacy Act (FOIPP).....01	210	54%
Alberta's Health Information Act (HIA).....02	24	6%
Alberta's Fair Trading Act.....03	2	1%
Alberta's Electronic Transactions Act.....04	2	1%
Personal Information and Protection of Electronic Documents Act (PIPEDA).....05	6	2%
Alberta's Protection of Personal Information.....06	7	2%
Other (specify):.....88	61	16%
Don't know/ Refused.....99	109	28%

**Q7:**

Overall, how much attention do you pay to the issue of the privacy and confidentiality of personal health care information? Do you pay ... (READ LIST)

N = .....	1004	100%
None.....1	82	8%
Very little.....2	200	20%
Some.....3	402	40%
or A lot.....4	316	31%
(DO NOT READ) Don't know/ Refused.....9	4	0%

**Q8:**

Using a 7 point scale where 1 is not important at all and 7 is very important, how important is to you that the personal health information you provide to the following health care providers be kept confidential

N = .....	1004	100%
Press Enter or hit OK to Continue .....	1004	100%

**Q8A:**

Physicians

N = .....	1004	100%
1 - Not important at all.....	35	3%
2.....	14	1%
3.....	15	1%
4 - Moderately important.....	27	3%
5.....	60	6%
6.....	113	11%
7 - Very important .....	736	73%
Don't know/ Refused.....	4	0%

**Q8B:**

Pharmacies or pharmacists

N = .....	1004	100%
1 - Not important at all.....	34	3%
2.....	12	1%
3.....	21	2%
4 - Moderately important.....	55	5%
5.....	133	13%
6.....	146	15%
7 - Very important .....	603	60%
Don't know/ Refused.....	0	0%

**Q8C:**

Hospitals and nursing homes

N = .....	1004	100%
1 - Not important at all.....	35	3%
2.....	18	2%
3.....	17	2%
4 - Moderately important.....	39	4%
5.....	92	9%
6.....	166	17%
7 - Very important .....	633	63%
Don't know/ Refused.....	4	0%



**Q8D:**

The Alberta Department of Health and Wellness

N = .....	1004	100%
1 - Not important at all.....1	34	3%
2.....2	14	1%
3.....3	23	2%
4 - Moderately important.....4	51	5%
5.....5	106	11%
6.....6	144	14%
7 - Very important.....7	621	62%
Don't know/ Refused.....9	11	1%

**Q9:**

I'm going to read you a series of statements and for each, I'd like you to tell me whether you strongly agree, somewhat agree, somewhat disagree or strongly disagree with the statement.

N = .....	1004	100%
Press Enter or hit OK to Continue.....1	1004	100%

**Q9A:**

I would agree to my health information being disclosed to Alberta Health and Wellness for planning and resource allocation

N = .....	1004	100%
Strongly Disagree.....1	152	15%
Somewhat Disagree.....2	114	11%
Somewhat Agree.....3	486	48%
Strongly Agree.....4	229	23%
Don't know/ Refused.....9	23	2%

**Q9B:**

I would agree to my health information being used for public health surveillance, which includes monitoring of communicable diseases and assessing lifestyle influences such as smoking

N = .....	1004	100%
Strongly Disagree.....1	173	17%
Somewhat Disagree.....2	134	13%
Somewhat Agree.....3	422	42%
Strongly Agree.....4	259	26%
Don't know/ Refused.....9	16	2%

**Q9C:**

I would agree to my health information being released without my consent to governments, provided that any information that could identify me has been removed

N = .....	1004	100%
Strongly Disagree.....1	243	24%
Somewhat Disagree.....2	119	12%
Somewhat Agree.....3	392	39%
Strongly Agree.....4	244	24%
Don't know/ Refused.....9	6	1%

**Q9D:**

I would agree that my consent be required before my health information is disclosed to someone doing health research

N = .....	1004	100%
Strongly Disagree .....	48	5%
Somewhat Disagree .....	55	5%
Somewhat Agree.....	228	23%
Strongly Agree .....	667	66%
Don't know/ Refused.....	6	1%

**Q9E:**

I would agree to my health information being disclosed without my consent to researchers, provided that any information that could identify me has been removed

N = .....	1004	100%
Strongly Disagree .....	207	21%
Somewhat Disagree .....	101	10%
Somewhat Agree.....	398	40%
Strongly Agree .....	289	29%
Don't know/ Refused.....	9	1%

**Q9F:**

I would agree that my consent be required before my health information is disclosed to law enforcement officers

N = .....	1004	100%
Strongly Disagree .....	59	6%
Somewhat Disagree .....	79	8%
Somewhat Agree.....	252	25%
Strongly Agree .....	608	61%
Don't know/ Refused.....	6	1%

**Q10:**

Do you believe it is appropriate to have your health information placed in an electronic health record (EHR) that can be accessed whenever you seek treatment? Please use a scale from 1 to 7 where '1' means "Not at all appropriate", '7' means "Completely appropriate" and the mid-point '4' means "Moderately appropriate".

N = .....	1004	100%
1 - Not at all appropriate .....	113	11%
2.....	19	2%
3.....	35	3%
4 - Moderately appropriate.....	244	24%
5.....	169	17%
6.....	135	13%
7 - Very appropriate.....	279	28%
Don't know/ Refused.....	10	1%

**Q11:**

How important is it for you to be able to exercise consent on who can obtain access to your electronic health record (EHR)?

N = .....		1004	100%
1 - Not important at all.....	1	17	2%
2.....	2	3	0%
3.....	3	14	1%
4 - Moderately important.....	4	85	8%
5.....	5	98	10%
6.....	6	128	13%
7 - Very important .....	7	656	65%
Don't know/ Refused.....	9	3	0%

**Q12:**

I'm going to read you a series of statements and for each, I'd like you to tell me whether you strongly agree, somewhat agree, somewhat disagree or strongly disagree with the statement.

N = .....		1004	100%
Press Enter or hit OK to Continue .....	1	1004	100%

**Q12A:**

I would agree to my health information being disclosed without my consent through an electronic system to a doctor or other health care provider who is involved in my treatment

N = .....		1004	100%
Strongly Disagree .....	1	175	17%
Somewhat Disagree .....	2	92	9%
Somewhat Agree.....	3	386	38%
Strongly Agree .....	4	344	34%
Don't know/ Refused.....	9	7	1%

**Q12B:**

I would agree to my health information being disclosed without my consent through an electronic system to a health care provider who is involved in my treatment within my health region

N = .....		1004	100%
Strongly Disagree .....	1	193	19%
Somewhat Disagree .....	2	116	12%
Somewhat Agree.....	3	394	39%
Strongly Agree .....	4	297	30%
Don't know/ Refused.....	9	4	0%

**Q12C:**

I would agree to my health information being disclosed without my consent through an electronic system to a health care provider who is involved in my treatment within Alberta

N = .....	1004	100%
Strongly Disagree .....	184	18%
Somewhat Disagree .....	128	13%
Somewhat Agree.....	387	39%
Strongly Agree .....	299	30%
Don't know/ Refused.....	6	1%

**Q12D:**

I would agree to my health information being disclosed without my consent through an electronic system to a health care provider who is involved in my treatment within Canada

N = .....	1004	100%
Strongly Disagree .....	235	23%
Somewhat Disagree .....	129	13%
Somewhat Agree.....	381	38%
Strongly Agree .....	253	25%
Don't know/ Refused.....	6	1%

**Q12E:**

I would agree to my health information being disclosed without my consent through an electronic system to a health care provider for secondary purposes such as health system management

N = .....	1004	100%
Strongly Disagree .....	359	36%
Somewhat Disagree .....	267	27%
Somewhat Agree.....	296	29%
Strongly Agree .....	59	6%
Don't know/ Refused.....	23	2%

**Q13:**

Of the following, please tell me which concerns you most about the existence of electronic health records (EHRs)? (READ LIST)

N = .....	1004	100%
Hackers .....	207	21%
Unauthorized access .....	371	37%
System failure.....	60	6%
Loss of information.....	73	7%
Computer theft.....	49	5%
All of the above (DO NOT READ) .....	220	22%
None of the above (DO NOT READ).....	7	1%
Other (specify).....	3	0%
(DO NOT READ) Don't know/ Refused.....	14	1%

**Q13A:**

Have you ever heard of Alberta's Health Information Act?

N = .....		1004	100%
Yes.....1		530	53%
No.....2	=> Q19	455	45%
Refused/ Don't know.....9	=> Q19	19	2%

**Q14:**

And, how familiar would you say you are with Alberta's Health Information Act? Would you say you are ... (READ LIST)

N = .....		530	100%
Not at all familiar.....1		82	15%
Not very familiar.....2		233	44%
Somewhat familiar.....3		190	36%
Very familiar.....4		25	5%
(DO NOT READ) Refused/ Don't know.....9		0	0%

**Q15:**

How satisfied are you with the effectiveness of Alberta's Health Information Act in protecting the privacy of personal health information?

N = .....		530	100%
1 - Very Dissatisfied.....1		23	4%
2.....2		11	2%
3.....3		25	5%
4 - Neither satisfied nor dissatisfied.....4		210	40%
5.....5		115	22%
6.....6		51	10%
7 - Very Satisfied.....7		35	7%
Don't know/ Refused.....9		60	11%

**Q16:**

How often have you used Alberta's Health Information Act to request access to your health information?

N = .....		530	100%
Very often.....1		6	1%
Sometimes.....2		32	6%
Rarely.....3		80	15%
Never.....4		410	77%
Refused.....9		2	0%

**Q17:**

I'm going to read you a list of possible sources of information about Alberta's Health Information Act. Please tell me which sources you rely on most for information on the Act. (READ LIST)

N = .....	530	100%
The Internet.....01	116	22%
Television.....02	138	26%
Radio.....03	95	18%
Newspapers.....04	176	33%
Alberta Health and Wellness.....05	103	19%
Physicians.....06	194	37%
Pharmacies.....07	108	20%
Word of mouth.....08	92	17%
Office of the Information and Privacy Commissioner.....09	26	5%
Work or Job.....10	86	16%
None of the above (DO NOT READ).....11	23	4%
Other (specify).....88	11	2%
(DO NOT READ) Don't know/ Refused.....99	7	1%

**Q18:**

Overall, how would you rate the quality of the information you receive from the Office of the Information and Privacy Commissioner on Alberta's Health Information Act?

=> +1		
si NOT Q17=09		
N = .....	26	100%
Poor.....1	2	8%
Fair.....2	9	35%
Good.....3	6	23%
Very Good.....4	5	19%
Excellent.....5	0	0%
(DO NOT READ) Don't know/ Refused.....9	4	15%

**Q19:**

Should legislation designed to protect the privacy of health information include: (READ LIST)

N = .....	1004	100%
The public sector.....1	38	4%
The private sector.....2	33	3%
Both the private and public sector equally.....3	828	82%
Neither.....4	62	6%
Don't know/ Refused (DO NOT READ).....9	43	4%

**Q20:**

How familiar would you say you are with the Office of the Information and Privacy Commissioner? Would you say you are... (READ LIST)

N = .....	1004	100%
Not at all familiar.....1	538	54%
Not very familiar .....2	293	29%
Somewhat familiar.....3	160	16%
Very familiar .....4	11	1%
(DO NOT READ) Refused/ Don't know.....9	2	0%

**Q21:**

Please tell me whether you agree or disagree with the following statement. \*\*I would like to know more about what the Office of the Information and Privacy Commissioner does.\*\* [PROBE: IS THAT STRONGLY OR SOMEWHAT]

N = .....	1004	100%
Strongly Disagree.....1	51	5%
Somewhat Disagree .....2	141	14%
Somewhat Agree.....3	407	41%
Strongly Agree .....4	391	39%
Don't know/ Refused.....9	14	1%

**Q22:**

Based on what you know about the Office of the Information and Privacy Commissioner and your impressions, would you agree that the Office acts independently from government?

N = .....	1004	100%
Yes.....1	354	35%
No.....2	313	31%
(DO NOT READ) Don't know/ Refused.....9	337	34%

**Q23:**

The mandate of the Office of the Information and Privacy Commissioner includes overseeing Alberta's Health Information Act, and to inform and educate the public about the Act. Keeping this in mind, overall, how satisfied are you with the performance of the Office. Please use a 7-point scale where 7 means you are very satisfied, 1 means you are very dissatisfied, and the mid-point 4 means you are neither satisfied nor dissatisfied.

N = .....	1004	100%
1 - Very Dissatisfied .....1	84	8%
2.....2	55	5%
3.....3	101	10%
4 - Neither satisfied nor dissatisfied.....4	480	48%
5.....5	147	15%
6.....6	32	3%
7 - Very Satisfied .....7	29	3%
Don't know/ Refused.....9	76	8%

**D1:**

Finally, I would like to ask some questions for statistical purposes. I'd like to remind you that all your answers are completely confidential. In what year were you born? (Record year - XXXX)

N = .....	1004	100%
Don't know/ Refused.....9999	26	3%

**D2:**

What is the highest level of formal education that you have completed? (READ LIST)

N = .....	1004	100%
Grade 8 or less.....1	28	3%
Some high school.....2	111	11%
Complete high school .....3	247	25%
Technical, vocational post-secondary, college .....4	285	28%
Some university.....5	84	8%
Complete university degree.....6	166	17%
Post graduate degree .....7	75	7%
(DO NOT READ) Refused .....9	8	1%

**D3:**

What is your current employment status? Are you (READ LIST - ACCEPT ONE ANSWER ONLY)

N = .....	1004	100%
Working full-time (35 or more hours per week).....01	425	42%
Working part-time (less than 35 hours per week).....02	102	10%
Self-employed .....03	146	15%
Unemployed, but looking for work.....04	37	4%
Attending school full-time/ A student.....05	29	3%
Retired.....06	149	15%
Not in the workforce (Full-time homemaker/ Unemployed, not looking for work).....07	93	9%
(DO NOT READ) Other (do not specify): .....88	13	1%
Refused .....99	10	1%



**Appendix B: Sample Size by Community**



CITY	Urban	Rural	TOTAL
ACME		1	1
AIRDRIE	6		6
ALDER FLATS		1	1
ALHAMBRA		1	1
ANDREW		1	1
ARDROSSAN	6		6
ARROWWOOD		1	1
ATHABASCA	3		3
BANFF		3	3
BARNWELL		1	1
BARRHEAD	1		1
BASHAW		1	1
BASSANO		2	2
BEAUMONT	3		3
BEAVERLODGE		6	6
BEISEKER		1	1
BENTLEY		2	2
BERWYN		1	1
BIG VALLEY		1	1
BITTERN LAKE		1	1
BLACK DIAMOND		1	1
BLACKFALDS		2	2
BLACKIE		2	2
BLAIRMORE		4	4
BLUESKY		1	1
BLUFFTON		2	2
BODO		1	1
BON ACCORD		2	2
BONANZA		2	2
BONNYVILLE	3		3
BOW ISLAND		1	1
BOWDEN		4	4
BOYLE		2	2
BRAGG CREEK		2	2
BROOKS	4		4
BURDETT		1	1
CALGARY	201		201
CAMROSE	4		4

CANMORE	3		3
CARDSTON		5	5
CARMANGAY		1	1
CAROLINE		2	2
CARSTAIRS		3	3
CASTOR		2	2
CAYLEY		2	2
CHAMPION		1	1
CHAUVIN		1	1
CHERRY GROVE		1	1
CLAIRMONT		1	1
CLARESHOLM		4	4
CLIVE		2	2
CLYDE		1	1
COALDALE	4		4
COCHRANE	5		5
COLD LAKE	4		4
COLEMAN		2	2
CONKLIN		1	1
CONSORT		1	1
CORONATION		2	2
COWLEY		1	1
CRAIGMYLE		1	1
CREMONA		2	2
CROOKED CREEK		1	1
CROSSFIELD		1	1
DAYSLAND		1	1
DE WINTON		1	1
DEBOLT		2	2
DELBURNE		1	1
DELIA		2	2
DIDSBURY		9	9
DIXONVILLE		2	2
DONNELLY		2	2
DRAYTON VALLEY	5		5
DRUMHELLER		7	7
DUCHESS		1	1
EAGLESHAM		2	2
ECKVILLE		2	2

EDMONTON	171		171
EDSON	2		2
ELK POINT		3	3
ELKWATER		1	1
ELNORA		1	1
EVANSBURG		3	3
FAIRVIEW		6	6
FERINTOSH		1	1
FORESTBURG		2	2
FORT ASSINIBOINE		2	2
FORT MACLEOD		4	4
FORT MCMURRAY	5		5
FORT SASKATCHEWAN	5		5
FORT VERMILION		4	4
FOX CREEK		4	4
FOX LAKE		1	1
GADSBY		1	1
GLEICHEN		2	2
GRANDE CACHE		5	5
GRANDE PRAIRIE	11		11
GRIMSHAW		2	2
HANNA		1	1
HARDISTY		3	3
HAY LAKES		1	1
HAYTER		1	1
HIGH LEVEL		2	2
HIGH PRAIRIE		6	6
HIGH RIVER	1		1
HILDA		1	1
HINTON	2		2
HOBHEMA		1	1
HOTCHKISS		1	1
HUSSAR		2	2
HYTHE		2	2
INNISFAIL	5		5
INNISFREE		1	1
IRON SPRINGS		1	1
IRRICANA		1	1
JASPER		4	4

KANANASKIS		1	1
KEG RIVER		1	1
LA CRETE		3	3
LAC LA BICHE		6	6
LACOMBE		13	13
LAMONT		1	1
LANGDON		3	3
LAVOY		1	1
LEDUC	7		7
LEGAL		4	4
LESLIEVILLE		2	2
LETHBRIDGE	21		21
LLOYDMINSTER	4		4
LONGVIEW		2	2
LOUSANA		1	1
MAGRATH		3	3
MANNING		2	2
MARWAYNE		3	3
MAYERTHORPE		1	1
MEDICINE HAT	20		20
MILK RIVER		1	1
MILLET		8	8
MILO		1	1
MONARCH		1	1
MORINVILLE	3		3
MORRIN		1	1
MULHURST BAY		1	1
MUNDARE		1	1
MYRNAM		2	2
NAMAQ		4	4
NAMPA		2	2
NANTON		7	7
NEW SAREPTA		1	1
NEWBROOK		1	1
NITON JUNCTION		3	3
NOBLEFORD		1	1
OLDS	5		5
ONOWAY		8	8
PEACE RIVER	1		1

PENHOLD		2	2
PICTURE BUTTE		2	2
PINCHER CREEK		5	5
PONOKA	1		1
PRIDDIS		1	1
PROVOST		2	2
RADWAY		1	1
RALSTON		1	1
RAYMOND		2	2
RED DEER	22		22
RED DEER COUNTY	1		1
RED EARTH CREEK		1	1
REDWATER		4	4
RIMBEY		4	4
RIVIERE QUI BARRE		1	1
ROCHESTER		2	2
ROCKY MOUNTAIN HOUSE	1	4	5
ROCKYFORD		3	3
ROLLING HILLS		1	1
SANGUDO		1	1
SCHULER		1	1
SEBA BEACH		1	1
SEDEGWICK		4	4
SEVEN PERSONS		2	2
SEXSMITH		3	3
SHERWOOD PARK	17		17
SLAVE LAKE		6	6
SMITH		1	1
SMOKY LAKE		1	1
SPEDDEN		1	1
SPRUCE GROVE	6		6
ST ALBERT	14		14
ST LINA		1	1
ST PAUL		7	7
STAND OFF		1	1
STANDARD		1	1
STAR		1	1
STAUFFER		1	1

STAVELY		1	1
STETTLER		6	6
STIRLING		1	1
STONY PLAIN	6		6
STRATHMORE	2		2
SUNDRE		6	6
SUNNYNOOK		1	1
SYLVAN LAKE	2		2
TABER	1		1
TEES		1	1
THORHILD		1	1
THORSBY		2	2
THREE HILLS		5	5
TILLEY		1	1
TOFIELD		5	5
TOMAHAWK		1	1
TROCHU		1	1
TURNER VALLEY		3	3
VALLEYVIEW		4	4
VAUXHALL		2	2
VERMILION	1		1
VIKING		1	1
VILNA		1	1
VULCAN		1	1
WABASCA		1	1
WAINWRIGHT	1		1
WATERTON PARK		1	1
WEMBLEY		1	1
WESTLOCK	3		3
WETASKIWIN	5		5
WHITECOURT	2		2
WILDWOOD		1	1
WILLINGDON		1	1
WINFIELD		1	1
WOKING		1	1
WORSLEY		3	3
<b>TOTAL</b>	<b>600</b>	<b>404</b>	<b>1004</b>