

**ALBERTA
INFORMATION AND PRIVACY COMMISSIONER**

**Report on the Collection, Use and Disclosure of Health Information
for the Alberta Cervical Cancer Screening Program**

December 12, 2005

**Investigation Report H2005-IR-002
(Investigation # H0541, H0544, H0553, H0559, H0560, H0561 & H0580)**

I. Introduction

[1] On August 6, 2004, the Information and Privacy Commissioner (Commissioner) received a complaint that the Alberta Cervical Cancer Screening Program (ACCSP), collected, used and disclosed health information in contravention of the *Health Information Act* (HIA). The Commissioner received additional complaints dated August 16, August 30, and September 8, 2004. The complaints concerned:

- Disclosure of registration information to the ACCSP
- Disclosure of laboratory results to the ACCSP
- Security of the information provided to the ACCSP
- Mandatory participation nature of the ACCSP

[2] Commissioner ordered an investigation into these matters under section 85(e) of the HIA. This report contains the findings of this Office.

[3] Additional letters and phone calls of complaint were received from affected individuals after the Commissioner had initiated an investigation. These individuals were told that an investigation had already been initiated and that the investigation report would be provided to them without more files being opened.

II. Executive Summary

[4] The ACCSP is a program operated by the Alberta Cancer Board (ACB). The program, which was implemented in late 2003, screens eligible women for cervical cancer. The program's goal is to 'reduce the incidence and mortality from cervical cancer'¹.

¹ <http://www.cancerboard.ab.ca/accsp/index.html>

[5] The complaints filed with our Office quite strongly express women's concern, that health information, particularly information related to the Papanicolaou test (Pap test) is being disclosed without consent to the ACCSP. This investigation examines the ACB's authority to collect, use and disclose health information necessary to operate the program, and specifically examines an individual's right to express a wish about how much health information should be disclosed.

[6] The investigation does not examine the Alberta Government's policy approach to cancer screening and surveillance or the merits of the ACCSP. While I believe the ACB makes a very convincing case for the program, this investigation is limited to an examination of the program's compliance with the HIA.

[7] I have found that the ACB has authority to collect, use and disclose health information to operate the ACCSP and that the ACB properly secured that information. The ACB made extensive efforts to examine and ensure they had taken reasonable steps to protect the privacy, confidentiality and security of health information, including the submission of a Privacy Impact Assessment (PIA) to our Office.

[8] However, I also found that the mandatory nature of the ACCSP, which requires the participation of every eligible woman in Alberta, does not meet the requirement of the HIA. The program, as implemented, allows women to opt-out of receiving correspondence such as a Pap test notice reminder, Pap test result notification and follow-up letters. However, women have no control over the disclosures of their information to the program. I found that the requirement in section 58(2) of the HIA to consider an expressed wish about how much health information should be disclosed could not be met with a standardized or policy approach that required participation in the program.

[9] I had intended to recommend that the ACB implement a full opt-out feature in the ACCSP that respected a woman's right to express her wish that information related to her Pap test not be disclosed to the program. However, I am pleased to say that the ACB decided to provide a full opt-out of the ACCSP while this matter was still under investigation. This report therefore does not contain any recommendations. Our Office will continue to monitor the ACB's progress towards implementing an opt-out solution.

[10] I acknowledge the ACB's cooperation and active approach in addressing the concerns expressed by women who filed complaints with our Office.

III. Background

[11] Cervical cancer or cancer of the cervix occurs in the cells that line the surface of the cervix. The ACB says that cancer of the cervix can occur when abnormal cell changes are not monitored or treated over a period of time, and that almost all cervical cancers can

be prevented by finding these cell changes early enough to be treated and cured². Cell changes are found through a diagnostic procedure called a Pap smear. A Pap smear or Pap test is taken by a health service provider scraping cells from the cervix that are then placed on a slide. The slide is sent to a laboratory where the cells are analyzed under microscope. There are three possible results to this analysis. The cells can be found normal, abnormal or unsatisfactory (sample not good enough to be read).

[12] The ACB says that there are about 120-150 new cases of cervical cancer in Alberta every year. About 40 women in Alberta die each year from cervical cancer. The ACB says most women who develop cervical cancer did not have a Pap test completed or did not have one as often as recommended³. The ACCSP helps address this issue by reminding women to have a Pap test or recommending follow-up, by communicating results to women and by reminding their physicians if the follow-up is overdue.

[13] The ACCSP was first announced by Alberta Health and Wellness (AHW) in February 2000. Program development was overseen by an Advisory Committee with members being appointed by the Assistant Deputy Minister, Population Health Division, AHW.

[14] On April 14, 2003, the ACB issued a press release announcing that the first stage of this province-wide program would be launched in the Calgary Health Region. In late 2003, the ACCSP was implemented with Calgary Laboratory Services (CLS) becoming the first laboratory to submit Pap test results to the program. Approximately 400,000 women in the Calgary and surrounding area received an introductory letter from the program, which was followed by a letter to women who had received a Pap test to advise of its results.

[15] The ACCSP's information system contains information about Pap test results, which the ACB says is used to:

- Send correspondence to physicians to ensure women with abnormal screening results have been followed up.
- Remind women and physicians if recommended follow-up is overdue.
- Send letters to women when it is time for their next routine screening.
- Send screening results to women.
- Assist in quality improvement of screening services and program evaluation.⁴

[16] During the spring of 2005, the ACCSP also deployed in the Palliser Health Region and later intends to deploy in the Capital Health Region and northern health regions.

² <http://www.cancerboard.ab.ca/accsp/resources.html> Pamphlet titled 'A New Program to Prevent Cervical Cancer'

³ <http://www.cancerboard.ab.ca/accsp/women9.html>

⁴ http://www.cancerboard.ab.ca/accsp/pdf/accsp_update4_june2003.pdf

[17] The complaints submitted to our Office were received following the ACCSP's launch in the Calgary area.

[18] The disclosures of health information by Alberta Health and Wellness, Calgary Health Region and/or Calgary Laboratory Services necessary to operate the program will be examined; however, the focus of this report is on the ACB. Alberta Health and Wellness, the Calgary Health Region and Calgary Laboratory Services were all involved in the operation of the ACCSP at the time complaints were received by our Office. This involvement occurs under the guidance of the ACB who operates the program. As the operator of the ACCSP, it is the ACB who is generally responsible for the collection, use, disclosure and security of health information necessary to operate the program. The ACB is also responsible for its affiliates, information manager and for the policies and procedures concerning the program.

[19] It is important to note that this report does not examine the Alberta Cancer Registry, which operates under the authority of Part 2 of the *Cancer Programs Act*. Both the Cancer Registry and the ACCSP involve health surveillance, but there are important differences. The Cancer Registry contains 'health information' about men and women who have been diagnosed with a type of cancer, and reporting this information to the Cancer Registry is compelled by the *Cancer Programs Act*. The ACCSP is a screening program that contains information about a target population, most of whom do not have cancer. While the Cancer Registry contains some of the same information as that collected by the ACCSP, my comments and findings should not be construed as being applicable to the operation of the Cancer Registry.

IV. Information Flow

[20] The operation of the ACCSP sees health information flow between a number of custodians and the patient. To fully consider whether the program operates in accordance with the HIA, it is helpful to first set out these information flows.

[21] Information Flow 10 - ACB discloses health information collected to AHW for information management and/or information technology purposes

V. Complainant Concerns

[22] This Investigation Report captures the complaints of several women relating to various aspects of the operation of the ACCSP. The following excerpts from the Complainant's correspondence highlight the nature of the concerns.

Requesting that my name be taken out of the entire program is not possible. When I decide to have a Pap, and my results, should be completely confidential to me and my doctor. It should NOT be shared with some cancer screening organization. I am really offended by this. I do not feel that anyone should be entitled to this information against my wishes.

I found this (the ACCSP initiation letter) offensive for two reasons:

- 1. the program is a negative option program, in other words, one is automatically included*
- 2. more importantly, the letter made it obvious that this third party had been given my name, contact information and health care number by AHW as well as presumably my gender and age.*

Since the information is coming from my body I, and not the government or others, should have full ownership to the rights to the distribution or sale of it, shouldn't I?

I am happy to participate in screening programs when I am given a choice in the matter. I signed myself in for the breast cancer screening program and have appreciated their services and reminder letters. I cannot understand why the ACCSP was not designed the same way. I would therefore reject the argument that some hypothetical greater good is served by this privacy violation.

Recently I received in the mail an envelope from the ACCSP addressed to me personally with correct spelling of my name and address. Upon opening it, I was appalled to find that my personal identity has been provided to this agency from the Alberta government, and that any results from medical tests for this particular disease obtained via regular visit to my family doctor – and the lab where he would send me for this test – would be shared back automatically to this agency with no permission needed from either me or him. The only choice I seem to have in this whole process is to choose not to be badgered again with letters of encouragement to have the above mentioned test or be informed of any irregular results if there are any.

What gives any medical agency the right or freedom to access names and address of a certain demographic of people to badger them to have certain medical testing done, then collect data by personal identity?

My doctor is extremely professional and I despise the fact that the Alberta Cancer Board seems to suggest that if it weren't for their prying into my private test results, I and hundreds of others would surely die from cervical cancer as a result of either my ignorance or the negligence of doctors.

I just have a problem with them (the ACB) getting it (the lab results) from confidential places I had trusted to be totally private, without my knowledge or consent beforehand. Telling me I would opt out of the program after they have already made the moves to violate privacy is insulting.

It really is shocking that police can no longer go through a person's pockets without sound reason because it might violate his rights, yet my... info may be given to as many researchers or health officials who desire it because this is considered "public" information.

[23] I have grouped the Complainants' concerns into the following issues, which form the basis for my analysis into the ACCSP:

1. Does the ACB have authority to collect 'health information' necessary to operate the ACCSP?
2. Does the ACB have authority to use 'health information' to operate the ACCSP?
3. Does the ACB have authority to disclose 'health information' to operate the ACCSP?
4. Does the ACB comply with the general duties of the HIA?
5. Does the ACB properly safeguard 'health information' in the ACCSP?

VI. Application of the HIA

[24] The HIA applies to 'health information' in the custody and control of a 'custodian'. In order to establish the Commissioner's jurisdiction in this matter, I must first establish that the information at issue is 'health information' and that the ACB is the 'custodian' of that information.

A. Is the information at issue ‘health information’ as defined by the HIA?

[25] ‘Health information’ is defined in section 1(1)(k) of the HIA and reads as follows:

“health information” means any or all of the following:

- (i) diagnostic, treatment and care information;*
- (ii) health service provider information;*
- (iii) registration information.*

[26] The information collected, used and disclosed in the operation of the ACCSP includes a women’s contact information and personal health number; information related to the Pap test result and health services provider who took the Pap smear and the laboratory that analyzed it. I have reviewed the information and find that the data elements which comprise the ACCSP include ‘diagnostic treatment and care information’, ‘health service provider information’ and ‘registration information’.

[27] I therefore find that the information collected, used or disclosed in the operation of the ACCSP is ‘health information’ as defined in the HIA.

B. Is the ACB a custodian under the HIA?

[28] The relevant portion of the HIA that defines a ‘custodian’ reads as follows:

1(1)(f) “custodian” means

- (vii) the Alberta Cancer Board continued under the Cancer Programs Act;*

[29] I find that the ACB is a ‘custodian’ of ‘health information’ as defined in the HIA.

VII. Assessment

Issue 1: Does the ACB have authority to collect ‘health information’ necessary to operate the ACCSP?

[30] The relevant portion of the HIA that addresses the collection of ‘health information’ reads as follows:

20 A custodian may collect individually identifying health information

- (a) if the collection of that information is expressly authorized by an enactment of Alberta or Canada, or*

(b) if that information relates directly to and is necessary to enable the custodian to carry out a purpose that is authorized under section 27.

[31] The ACB collects 'health information' from AHW that it uses to contact women eligible for cervical cancer screening. This information includes:

- Personal health number and unique lifetime identifier
- Name, birth date, mailing address, phone number, and
- Last cervical screening date, next screening date, last screening result, last date of follow-up and next date of follow-up

[32] The ACB also collects 'health information' from the laboratory that it uses to provide health services, including screening related activities. This information includes:

- Unique lifetime identifier and date of birth
- Health service provider identifier, address and phone number
- Specimen unique identifier, pathology report number, service description, service result, specimen adequacy, follow-up recommendation and recall interval

[33] The ACB in its submission to me said that section 20(b) and 22(g) of HIA authorize collection of this 'health information'. Section 20(b) authorizes a 'custodian' to collect 'health information' that is directly related to and necessary to carry out a purpose authorized under section 27. Section 22(2)(g) authorizes a 'custodian' to collect 'health information' where the disclosure of that information is authorized under Part 5.

[34] On July 30, 2003 the ACB submitted a Privacy Impact Assessment (PIA) to the Commissioner for review and comment. The PIA provided analysis of the ACB's authority to collect 'health information' necessary to operate the ACCSP. The results of this analysis are consistent with the ACB's recent submission to me on this investigation. The PIA was accepted by the Commissioner on September 23, 2003. Acceptance of the PIA recognizes the due diligence taken by the ACB to examine its authority to collect 'health information' prior to implementing the program. This investigation examines whether this due diligence resulted in the ACB implementing decisions that comply with the HIA.

[35] Section 20 of the HIA provides authority to collect 'health information' where expressly authorized by an enactment of Alberta or Canada or where the information relates directly to and is necessary to carry out a purpose authorized under section 27. Section 27 establishes the purposes for which 'health information' can be used. Collection can therefore be authorized expressly by law or wherever a 'custodian' has authority under section 27 to use 'health information'. For example, collection of 'health information' necessary to provide a health service would be authorized, as section 27(1)(a) authorizes a custodian to use 'health information' to provide health services.

[36] As the ACB has relied on section 20(b) of the HIA as its authority to collect 'health information', I must therefore first examine whether it used the information for one of the purposes authorized under section 27. The ACB will be found to have authority to collect 'health information' if the information collected was directly related to and necessary to carry out one of the authorized purposes listed in section 27. The relevant purposes within section 27 read:

27(1) A custodian may use individually identifying health information in its custody or under its control for the following purposes:

(a) providing health services;

(b) determining or verifying the eligibility of an individual to receive a health service;

(f) carrying out any purpose authorized by an enactment of Alberta or Canada;

(g) for internal management purposes, including planning, resource allocation, policy development, quality improvement, monitoring, audit, evaluation, reporting, obtaining or processing payment for health services and human resource management.

(2) A custodian referred to in section 1(1)(f)(iii), (iv), (vii), (xii) or (xiii) may, in addition, use individually identifying health information in its custody or under its control to carry out the following functions within the geographic area in which the custodian has jurisdiction to promote the objectives for which the custodian is responsible:

(a) planning and resource allocation;

(b) health system management;

(c) public health surveillance;

(d) health policy development.

[37] The ACB also says that section 27(1)(a)(b)(f)(g) and section 27(2) of the HIA authorize the use of 'health information' to operate the ACCSP.

[38] The ACCSP is a program with a broad mandate. The program aims to reduce the incidence of and mortality from cervical cancer and uses 'health information' to meet this purpose. The ACB in its submission to me said the program uses 'health information' to:

1. Review Pap test results. For the 90-95% of women with normal results, 'health information' is used to send results and reminder letters. For an abnormal result, the information is grouped into categories dependant upon the follow-up and treatment that is required, then results and reminder letters are sent to the woman the information is about. "Health information" is used to establish the category and monitor compliance with expected follow-up and treatment.
2. Monitor health service provider follow-up of the abnormal results. 'Health information' is used to ensure expected treatment is provided. This is described as a safety net to ensure women with abnormal results receive diagnosis and treatment.
3. Support health services as part of a population health program. 'Health information' is used to determine higher risk candidates and target training programs to encourage prevention, education and health promotion measures.
4. Provide quality assurance. 'Health information' is used to monitor use of appropriate techniques for collection of Pap smears, standards for interpretation of Pap smears and use of appropriate procedures for treatment.
5. Provide health system management and public health surveillance, including planning and resource allocation and policy development. 'Health information' is used to improve prevention and early detection of cervical cancer. The ACB says this results in fewer resources to screen women in low risk groups with consistent normal results and affords effective targeting and allocation of resources to where they are needed.

[39] The ACB operates programs under its primary legislation, the *Cancer Programs Act*. The relevant portion of the *Cancer Programs Act* reads:

8(1) Subject to any order, regulation or agreement made pursuant to section 21, the board shall...

(d) operate programs for the detection and diagnosis of cancer and the treatment and care of cancer patients...

[40] Section 8(1)(d) of the *Cancer Programs Act* is explicit in stating the purpose of the board to detect, diagnose and treat cancer and imposes a duty on the ACB to operate programs to meet this purpose. Section 27(1)(f) of the HIA authorizes a 'custodian' to use 'health information' to carry out any purpose authorized by an enactment of Alberta or Canada.

[41] I have reviewed the purposes for which 'health information' is used by the ACB to operate the ACCSP and find that these uses are authorized by section 27(1) & (2) of the HIA. Section 20(b) provides a 'custodian' with authority to collect 'health information' if

that information is directly related to and necessary to enable the custodian to carry out a purpose authorized in section 27. I am satisfied that the information collected by the ACB is directly related to and necessary to meet the duty imposed by the *Cancer Programs Act* to operate programs to detect, diagnose and treat cancer.

Issue 2: Does the ACB have authority to use ‘health information’ to operate the ACCSP?

[42] As outlined above, I have found that section 27 authorizes the ACB to use ‘health information’ to operate the ACCSP.

Issue 3: Does the ACB have authority to disclose ‘health information’ to operate the ACCSP?

[43] The relevant portion of the HIA reads:

33 A custodian may disclose individually identifying health information to the individual who is the subject of the information or to a person referred to in section 104(1)(c) to (i) who is acting on behalf of that individual.

35(1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual who is the subject of the information

(a) to another custodian for any or all of the purposes listed in section 27(1) or (2), as the case may be,

[44] Operation of the ACCSP involves the following three disclosures by the ACB:

1. Disclosure of ‘health information’ to the patient
2. Disclosure of ‘health information’ to the patient’s physician
3. Disclosure of ‘health information’ to AHW

Disclosure of the ‘health information’ to the patient

[45] The ACB discloses ‘health information’ when it sends ACCSP invitation, reminder, follow-up, recall and Pap test results letters to the patient. All these disclosures are disclosures of ‘health information’ to the individual who is the subject of the information. The ACB says this disclosure is authorized under section 33 of the HIA.

[46] Section 33 says that a ‘custodian’ may disclose individually identifying ‘health information’ to the individual the information is about. I therefore find that the ACB had authority to disclose ‘health information’ to the patient.

Disclosure of ‘health information’ to the patient’s physician

[47] The ACB discloses ‘health information’ to the patient’s physician when it sends ACCSP reminder, follow-up, results and return to screening correspondence. The ACB says these disclosures are authorized under section 35(1)(a) of the HIA.

[48] Section 35(1)(a) says that a ‘custodian’ may disclose individually identifying ‘diagnostic treatment and care information’ to another ‘custodian’ without consent for any purpose listed in section 27(1) or (2). Relevant portions of section 27 say that ‘health information’ can be used for the purpose of:

- providing health services (27(1)(a))
- carrying out any purpose authorized by an enactment of Alberta or Canada (27(1)(f))

[49] The ACB says that ‘health information’, including information related to the Pap test result, is disclosed to the patient’s physician to support the physician’s provision of health services to the patient. This includes monitoring that appropriate follow-up and necessary treatment ensues.

[50] As previously mentioned, the *Cancer Programs Act* requires the ACB to ‘operate programs for the detection and diagnosis of cancer and the treatment and care of cancer patients’. The ACB’s disclosure of ‘health information’ to the patient’s physician is one of the steps taken by the ACB in its efforts to meet this obligation. The ACB takes steps to ensure that the physician has received the Pap test result and that appropriate follow-up and treatment is provided, as well as reminding the physician when the patient’s next test is due. The physician uses the ‘health information’ disclosed by the ACB to provide health services to the patient.

[51] Section 35(1)(a) of the HIA authorizes a ‘custodian’ to disclose ‘health information’ without consent for the purpose of providing a health service and to carry out a purpose authorized by an enactment of Alberta or Canada. These are both purposes listed in section 27(1) of the HIA.

[52] I therefore find that the ACB had authority to disclose ‘health information’ to the patient’s physician.

Disclosure of ‘health information’ to AHW, as the ACB’s information manager

[53] The ACB discloses ‘health information’ to AHW under an information manager agreement.

[54] Section 66 of the HIA provides authority for a ‘custodian’ to enter into an agreement with an information manager to provide information management services. Section 66 reads:

66(1) In this section “information manager” means a person or body that

(a) processes, stores, retrieves or disposes of health information,

(b) in accordance with the regulations, strips, encodes or otherwise transforms individually identifying health information to create non-identifying health information, and

(c) provides information management or information technology services.

(2) A custodian may enter into an agreement with an information manager in accordance with the regulations for the provision of any or all of the services described in subsection (1).

(3) A custodian that has entered into an agreement with an information manager may disclose health information to the information manager without the consent of the individuals who are the subjects of the information for the purposes authorized by the agreement.

[55] The agreement between the ACB and AHW for information management services was effective on September 15, 2003, and includes:

- operate and manage the Cervical Cancer Screening (CCS) application;
- use all best efforts to provide a portal to the CCS accessible securely through the internet (with the security safeguards described in the Privacy Impact Assessment), or other means as may be established in the future;
- permit the ACB to access the CCS application;
- permit the ACB to add, delete or edit Information in the CCS application;
- regularly provide extracts of the information to the ACB for analysis purposes;
- enable an electronic log (i.e. audit trail) of all accesses to the CCS application and audit accesses in the event of a suspected security breach; and
- ensure that only authorized users are permitted access and immediately advise the ACB on determining an unauthorized access.

[56] The services provided by AHW under the agreement are information management or information technology services consistent with the services described within section 66 of the HIA. Section 66(3) provides authority for a ‘custodian’ to disclose ‘health information’ without consent for the purposes authorized by the information manager

agreement. I therefore find that the ACB has authority to disclose 'health information' to AHW, as the ACB's information manager.

Issue 4: Does the ACB comply with the general duties of the HIA?

[57] Part 6, Division 1 of the HIA places general duties related to 'health information' on a 'custodian'. Two of these duties are relevant to this investigation: 1) the section 58(1) duty to collect, use or disclose 'health information' in a limited manner, and 2) the section 58(2) duty to, in deciding how much 'health information' to disclose, consider the expressed wish of the individual the information is about.

[58] I have found that the ACB has authority to collect, use and disclose 'health information' to operate the ACCSP. A custodian must also ensure that it collects, uses and discloses this information in a limited manner and that it considers an individual's expressed wish about how much 'health information' to disclose.

A. Did the ACB comply with the duty to collect use or disclose 'health information' in a limited manner?

[59] The duty of a 'custodian' to collect, use or disclose 'health information' in a limited manner is addressed in section 58(1) of the HIA, which reads as follows:

When collecting, using or disclosing health information, a custodian must, in addition to complying with section 57, collect, use or disclose only the amount of health information that is essential to enable the custodian or the recipient of the information, as the case may be, to carry out the intended purpose.

[60] This section obligates a custodian to assess the amount of 'health information' that is essential to meet the purpose. In my view, a 'custodian' should have a measure of latitude to make this determination, which is one that requires medical expertise. I do not believe it is my role to determine what 'health information' is essential to provide a health service or to meet one of the other purposes described in the legislation. I have therefore decided to limit my review to examining whether the ACB took reasonable steps to assess what 'health information' was essential to collect, use and disclose in order to operate the ACCSP.

[61] The steps taken by the ACB to examine this matter include:

- investigation of approaches to cervical screening in other countries such as New Zealand and Australia;
- contracted with National Public Relations to investigate confidentiality concerns of physicians related to young women;
- held two focus groups involving young women;
- reviewed Canadian approaches to cervical screening;

- conducted several surveys involving women in Alberta; and
- completion of a Privacy Impact Assessment clarifying the data elements to be collected, used and disclosed, which was subsequently accepted by the Commissioner.

[62] It is evident that the ACB took a number of steps to assess the amount of ‘health information’ that was essential to collect, use and disclose in order to operate the ACCSP. I have reviewed these steps and am satisfied that the ACB reasonably examined this matter. I therefore find that the ACB complied with the duty to collect, use and disclose ‘health information’ in a limited manner.

B. Did the ACB comply with the duty to consider an expressed wish in determining how much ‘health information’ to disclose?

[63] Section 58(2) of the HIA requires a ‘custodian’ to consider the expressed wish of an individual related to the disclosure of ‘health information’. Section 58(2) reads:

58(2) In deciding how much health information to disclose, a custodian must consider as an important factor any expressed wishes of the individual who is the subject of the information relating to disclosure of the information, together with any other factors the custodian considers relevant.

[64] Several of the Complainants in this case raised concern with the mandatory nature of the ACCSP. While the program offered the individual the ability to opt-out of receiving correspondence, it did not allow an individual to opt-out of the program and therefore exercise control over the disclosure of ‘health information’ to the program. The women who contacted our Office stated their belief that they should be able to say whether their ‘health information’ is disclosed and should be able to opt-out of the program.

[65] Section 58(2) does not speak to collection or use of ‘health information’; it is specific to disclosure, and then only to the amount of ‘health information’ to disclose. However, there is no ceiling or limit to this wish. In considering the amount, it is possible for an individual to express their wish that some, most or all ‘health information’ not be disclosed. An individual is entitled to request that no ‘health information’ be disclosed. The ‘custodian’ must make a decision after taking all factors into consideration. The provision requires a ‘custodian’ to consider the expressed wish as an important factor, but not the only factor, and therefore the requirement may be met even though the expressed wish is not granted.

[66] The ACB obtains information necessary to operate the ACCSP. While the program uses and discloses this information to the women it is about and to their health service provider, it is the initial disclosures of ‘health information’ to the program that are central to the concerns that have been expressed.

[67] Section 58(2) applies to the ‘custodian’ who is making the decision about how much ‘health information’ to disclose. It does not apply to the recipient of the information. The disclosures of primary concern in this investigation are made by AHW (‘registration information’) and the laboratory (‘diagnostic treatment and care information’) and therefore it appears that these custodians are responsible to consider a woman’s expressed wish. There is merit in this logic; however, from a practical point of view this is problematic because it is the ACB who is responsible for the ACCSP and who decided what ‘health information’ was essential to operate the program. While it is evident that AHW and the laboratory disclose ‘health information’ to the ACB, they have done so under the direction of the ACB.

[68] The ACB is responsible to implement a program that complies with the HIA. In my view, this responsibility includes ensuring that the program is implemented in a manner that meets the HIA requirement to consider an expressed wish. The HIA requires a ‘custodian’ to establish or adopt policies and procedures to facilitate implementation of the Act and to maintain administrative, technical and physical safeguards to protect ‘health information’. As the custodian who operates the ACCSP, the ACB is responsible to have policies and procedures and to ensure they comply with the HIA. These policies and procedures provide direction for the ACB’s affiliates and the other custodians who disclose ‘health information’ to the program, including the requirement to consider an expressed wish. The June 3, 2004, minutes of the ACCSP Advisory Committee show that the ACB recognized this responsibility when the Committee deliberated and then decided how an expressed wish would be handled. As the ACB is responsible for program policies and procedures, I will examine whether the ACB implemented a program that complies with the section 58(2) duty to consider an individual’s expressed wish.

[69] The ACB did not take the obligation to consider an expressed wish lightly. The ACB undertook to study whether the program should provide a full or partial opt-out. I have examined the steps taken to consider this question, as I believe these steps are a relevant consideration in determining whether the ACB properly applied discretion in answering women’s requests to opt-out of the program. The steps taken by the ACB along with the results of each study include:

- 1) March 1999 Criterion Research Corporation conducted seven focus groups with various segments of women across Alberta. Relevant findings included:
 - favorable response to idea of an organized screening program
 - confidentiality was a major concern
 - automatic registration into the program raised concern as to whether program violates doctor/patient confidentiality, but recognized that any alternative to automatic registration would not be successful
 - strongly agreed that there must be an option to opt-out of the program
- 2) March 2000 Criterion Research Corporation conducted six focus groups with physicians. Relevant findings included:

- general reaction to the program was positive
 - opting out should be between the patient and the program
 - confidentiality and security of information on central database was a major concern and physicians wanted to know how the program would address it
- 3) 2003 National Public Relations held two discussion groups with young women. Relevant findings included:
- had positive reaction to the program
 - no concern with letters
 - felt that it was important to be able opt-out of the program. Said they would not choose to opt-out, but wanted the option

[70] The ACB also examined consent approaches to cervical cancer screening in other jurisdictions. In a presentation to me on October 13, 2004, the ACB advised me of New Zealand's experience where women initially had to request to be placed on the cervical cancer screening register by signing consent on the lab requisition. Approximately 20 to 40% of women chose to have their Pap test results sent to the register, which resulted in such a small representation that the program was not effective. Consultation and debate led to legislation that required health service providers to advise women that their Pap test result would be forwarded to the register unless they chose to opt-out. Within 6 years, 91% of women were enrolled in the program, which continues to operate with woman having the ability to opt-out.

[71] The ACB also provided me with information about the operation of cervical cancer screening programs in Canada. Two programs of note are the 'Manitoba Cervical Cancer Screening Program' and the 'Prevention Program for Cervical Cancer in Saskatchewan'. In Manitoba, the program operates with an opt-out. In Saskatchewan, the program was implemented with no opt-out, which led to complaints similar to those we received in Alberta. The Information and Privacy Commissioner of Saskatchewan conducted an investigation into the complaints and made a number of recommendations, including that the program implement a meaningful opt-out⁵.

[72] The information the ACB provided to me showed that confidentiality and security were key concerns and women should have the ability to opt-out of the program. However, this information was not the only factor considered by the ACB. The ACB also considered value-based impacts to the program that could occur if women chose to opt-out. The program's goal to reduce the incidence and mortality from cervical cancer and the effectiveness of a population-based surveillance program could be lessened by a percentage of women choosing to opt-out of the program. The ACB weighed this information and decided that a full opt-out of the program would not be provided. What must be examined is whether the mandatory participative approach adopted by the ACB meets the HIA requirement to consider an individual's expressed wish.

⁵ <http://www.oipc.sk.ca/reviews.htm>

[73] What must a custodian do to demonstrate that it has considered an expressed wish? Merriam Webster defines the term 'consider' as: "1: to think carefully: as **a**: to think of especially with regard to taking some action **b**: to take into account". Consideration involves an examination of more than one action. If there were only one possible action to take, there would be nothing to consider.

[74] The HIA provides a custodian with latitude to decide the course of action to take in response to an expressed wish. There can be differing opinions as to the course of action that should be taken. In my view, the legislative requirement to consider the expressed wish as an important factor, but not the only factor, means that a custodian must apply discretion when considering the wish.

[75] As previously noted, the ACB's approach did not allow women to opt-out of the ACCSP. In fact, the minutes of the ACCSP Advisory Committee on June 3, 2004, show that this question was considered and a decision made that an expressed wish to not have 'health information' disclosed to the program would be denied unless there were 'extreme extenuating circumstances' where inclusion in the program would be a safety risk. Effectively, the Committee decided to take a policy approach verses a case-by-case examination in deciding that there would be no opt-out of the program. With the exception of one case where the ACB agreed there was risk of imminent harm, indeed all such expressed wishes have been denied since that time.

[76] In Orders 97-001 and 2000-021 the Commissioner discusses the law on discretion as follows: "[t]he very concept of administrative discretion involves a right to choose between more than one possible course of action upon which there is room for reasonable people to hold differing opinions as to which is to be preferred." The Commissioner goes on to say that discretion cannot be abused 'by making an arbitrary or irrational decision' and outlines five types of abuse of discretion. The fifth abuse, which I believe is relevant to this discussion, is:

"where a delegate fetters his discretion by rigidly adopting a policy which precludes a consideration of the individual merits of the case."

[77] There must be more than one possible action to properly apply discretion and demonstrate that an expressed wish has been fairly considered. The ACB, in deciding that nobody would be allowed to opt-out of the ACCSP, effectively took a policy approach that denied women the right to have their expressed wish considered. There must be more than one possible outcome in order for consideration to be given. In my view, discretion was fettered when the ACB adopted a policy approach that did not afford fair consideration of each expressed wish made.

[78] I find that the ACB did not implement a program that complied with the duty to consider an expressed wish as an important factor in deciding how much 'health information' to disclose.

Issue 5: Does the ACB properly safeguard ‘health information’ in the ACCSP?

[79] The relevant portion of the HIA that addresses safeguarding of ‘health information’ reads:

60(1) A custodian must take reasonable steps in accordance with the regulations to maintain administrative, technical and physical safeguards that will

- (a) protect the confidentiality of health information that is in its custody or under its control and the privacy of the individuals who are the subjects of that information,*
- (b) protect the confidentiality of health information that is to be stored or used in a jurisdiction outside Alberta or that is to be disclosed by the custodian to a person in a jurisdiction outside Alberta and the privacy of the individuals who are the subjects of that information,*
- (c) protect against any reasonably anticipated*
 - (i) threat or hazard to the security or integrity of the health information or of loss of the health information, or*
 - (ii) unauthorized use, disclosure or modification of the health information or unauthorized access to the health information,*

and

- (d) otherwise ensure compliance with this Act by the custodian and its affiliates.*

(2) The safeguards to be maintained under subsection (1) must include appropriate measures

- (a) for the security and confidentiality of records, which measures must address the risks associated with electronic health records, and*
- (b) for the proper disposal of records to prevent any reasonably anticipated unauthorized use or disclosure of the health information or unauthorized access to the health information following its disposal.*

(3) In subsection (2)(a), “electronic health records” means records of health information in electronic form.

[80] Section 60 of the HIA requires custodians to take reasonable steps to maintain safeguards to protect 'health information'. In this case the ACB is required to ensure that reasonable steps have been taken to safeguard the 'health information' collected, used and disclosed within the ACCSP. In investigation report H2003-IR-003, I said that the safeguards necessary to protect 'health information' in an electronic medical record system will be determined through completion of a PIA. PIA requirements are outlined in section 64 of the HIA and read as follows:

64(1) Each custodian must prepare a privacy impact assessment that describes how proposed administrative practices and information systems relating to the collection, use and disclosure of individually identifying health information may affect the privacy of the individual who is the subject of the information.

(2) The custodian must submit the privacy impact assessment to the Commissioner for review and comment before implementing any proposed new practice or system described in subsection (1) or any proposed change to existing practices and systems described in subsection (1).

[81] As previously noted, the ACB submitted a PIA to the Commissioner with respect to the ACCSP on July 30, 2003. The July 30 submission meets the HIA requirement, as the PIA was received for review and comment prior to the ACB implementing the program in late 2003.

[82] The PIA included a risk analysis and details surrounding the safeguards being maintained by the ACB to protect the privacy, confidentiality and security of 'health information' within the ACCSP. This very thorough PIA was reviewed and then accepted by the Commissioner on September 23, 2003. The Commissioner's review included the steps taken by the ACB to safeguard 'health information'.

[83] I find that the ACB has met the requirements of the HIA to complete a PIA and has taken reasonable steps to maintain safeguards to protect the privacy, confidentiality and security of 'health information' within the ACCSP.

VIII. Conclusion

[84] I have found that the ACB has authority to collect, use and disclose 'health information' to operate the ACCSP, and that reasonable steps were taken to maintain safeguards to protect this information. The ACB very thoroughly examined confidentiality, privacy and security issues related to the operation of the ACCSP.

[85] The only area of concern, albeit a significant one, was the ACB's approach to handling a woman's expressed wish to not have her 'health information' disclosed to the ACCSP. I believe that the HIA requirement to consider an individual's expressed wish about how much 'health information' should be disclosed precludes a standardized or policy approach. This means that for the ACCSP, there cannot be a program approach

that does not allow a woman the right to meaningfully request an opt-out of the program and therefore exercise a measure of control over the disclosure of her 'health information'.

[86] Providing an opt-out should not be viewed as the only way in which a custodian may properly apply discretion and meet the requirement of the HIA to consider an expressed wish. In developing program policies and procedures, a custodian should consider the circumstances of the program being implemented and examine all of the options to handle an expressed wish. The ACB has examined how an expressed wish should be handled for the ACCSP, and in my view has now appropriately chosen to provide an opt-out of the program.

[87] I am very pleased to say that during the course of my investigation, the ACB decided to offer a full opt-out or exclusion from the ACCSP. The ACB is working on a long-term solution that will ensure that the information related to a woman's Pap test is not included in the database when she has requested exclusion from the program. The ACB has advised me that this will require technical changes to the database that it intends on having implemented by the end of March 2006. In the interim, the ACB will handle an expressed wish as follows:

- A woman requesting full exclusion from the program will be required to sign, date and return a form requesting exclusion of the information related to her Pap test, and acknowledge that she understands the consequences of not participating in the program
- ACB will then instruct its information manager to delete the information related to the Pap test from the ACCSP database

[88] I have no recommendations in this report, as the ACB has already taken steps to implement an opt-out of the ACCSP. The current solution put forth by the ACB is only reasonable as an interim measure. Our Office will remain involved with the ACB in monitoring the long-term solution until it has been successfully implemented.

Submitted by,

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Director, Health Information Act