

# **INFORMATION AND PRIVACY COMMISSIONER OF ALBERTA**

## **Investigation Report Concerning Collection, Use & Disclosure of Health Information to Conduct Quality Assurance Survey**

**August 30, 2007**

**Health Quality Council of Alberta  
&  
David Thompson Health Region**

**Investigation Report H2007-IR-001**

**(Investigations H1606 & H1607)**

### **I Introduction**

[1] On April 2, 2007, the Information and Privacy Commissioner received a request to investigate the collection, use and disclosure of health information, and steps taken to secure that information collected from a survey being conducted by the Health Quality Council of Alberta (HQCA). The HQCA hired Prairie Research Associates in Manitoba to administer the survey.

[2] The complainant received an 80-question survey by mail, with a covering letter that included his name and home phone number, and identified previous trips to an emergency department in the David Thompson Health Region (DTHR). The complainant questioned how the HQCA obtained this information without his permission. The complainant also noted concern that his information is not being properly safeguarded and questions “what right do they have passing around my information so casually”?

[3] The Commissioner authorized me to conduct an investigation under section 85(e) of the *Health Information Act* (HIA). Section 85(e) allows the Commissioner to investigate whether health information has been collected, used, disclosed, or created by a custodian in contravention of HIA. This report outlines findings and recommendations resulting from my investigation.

### **II Background**

[4] The HQCA was established by Ministerial Order in February 2004. The HQCA’s 2004-2005 Annual Report says it is “... an independent organization engaged in gathering knowledge and translating it into practical actions that can improve the quality, safety and performance of Alberta’s health system.”<sup>1</sup> Its

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<sup>1</sup> <http://www.hqca.ca/index.php?id=26> [HQCA 2004-2005 Annual Report]

mandate is to "... report directly to Albertans on the quality and performance of health services. The Council will identify best practices, and review and monitor health care quality including access, acceptability, appropriateness, effectiveness, efficiency and patient safety."<sup>2</sup>

[5] In 2003/2004 the Health Services Utilization and Outcomes Commission<sup>3</sup> conducted a "Satisfaction with Health Services Survey" and subsequently reported that Albertans were concerned with services received in emergency departments.<sup>4</sup> In its submission to me, the HQCA said emergency departments in Canada face significant challenges with wait times, crowding and related quality of service issues, and more in-depth study of the patient experience in Alberta was needed. A working group was established in 2006 to evaluate how an emergency department patient experience survey should be conducted and a survey was designed.

[6] The HQCA says many factors impact the emergency department patient experience. The survey design recognizes that the patient experience must be broadly evaluated, including patient characteristics, context of the visit, population, role of the facility in the community and the facility's unique characteristics. Reliable data about the patient's experiences at a particular facility and information about the facility, as well as wait time information from administrative regional health information systems allows grouping of facilities by function, population and acuity of patients.<sup>5</sup> This enables a meaningful comparison of results.

[7] The 80-question survey was mailed to a randomly selected sample of approximately 50,000 patients who received health services between January 26 and February 9, 2007, in any one of 61 Alberta emergency departments. The HQCA collected patient contact information from regional health authorities in order to complete the mail-out. A letter from the Chief Executive Officer of the HQCA accompanied each survey, which outlined the intent of the survey and indicated it was voluntary. The letter contained the name and mailing address of the patient, as well as the name of the emergency department facility recently attended. A pre-paid return envelope was provided to return the survey.

[8] The complaint received by the Commissioner concerns the collection, use, disclosure and security of health information under HIA. The complainant expressed concern with health information provided to the HQCA by the DTHR, and the subsequent use and security of that information. The complainant did not express concern about information collected directly from him in the survey. Completion of the survey is voluntary. The complainant could agree to answer the

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<sup>2</sup> <http://www.hqca.ca/index.php?id=26> [HQCA 2004-2005 Annual Report]

<sup>3</sup> Name changed to HQCA in February of 2004

<sup>4</sup> <http://www.hqca.ca/index.php?id=36> [HQCA Satisfaction with Health Services Survey]

<sup>5</sup> In this context, acuity refers to a formalized assessment of illness severity conducted by a clinician.

questions, or not, as he wished. Nevertheless, to provide a comprehensive report, I decided to examine all information related to the HQCA's survey regardless of the manner of collection or whether it related specifically to the complaint. This includes examination of a small amount of personal information subject to the *Freedom of Information and Protection of Privacy Act* (FOIP).

### **III Application of HIA & FOIP**

[9] The *Health Information Act* (HIA) applies to health information in the custody or control of a "custodian". The *Freedom of Information and Protection of Privacy Act* (FOIP) applies to personal information in the custody or control of a "public body".

[10] I have reviewed the information collected to complete the survey and found it includes "registration information" and "diagnostic, treatment and care information". I find this is health information, as defined in section 1(1)(k) of HIA.

[11] Level of education, type of residence, language spoken and the individual's personal opinion about the issue or facility being surveyed is also collected by the questionnaire. I have reviewed this information and find it is personal information, as defined in section 1(n) of FOIP.

[12] The HQCA is a provincial health board established under section 2 of the *Health Quality Council of Alberta Regulation* (130/2006), and consequently falls within the HIA definition of "custodian" under section 1(1)(f)(iv). As a provincial health board, the HQCA is also a "public body", as defined in section 1(1)(p) of FOIP.

[13] The HQCA has custody and control of health and personal information, and is a custodian and public body. Therefore, I find HIA and FOIP apply to the HQCA.

### **IV Issues**

1. Did the DTHR disclose the complainant's health information in contravention of Part 5, Division 1 of HIA?
2. Did the HQCA collect the complainant's health or personal information in contravention of Part 3 of HIA and Part 2, Division 1 of FOIP?
3. Did the HQCA fail to safeguard health or personal information in contravention of sections 60 of HIA and 38 of FOIP?

## **V Analysis**

### Flow of Information Necessary to Complete Survey

[14] Information is initially disclosed from regional health authorities to the HQCA, who collects the information. The disclosure and subsequent collection includes the following information:

- patient name, birth date, gender, personal health number, phone number and address;
- arrival mode, emergency department facility visited, registration date, triage date, inpatient admittance and discharge date; and
- reason for visit, triage level and diagnosis.

[15] The second collection by the HQCA is from the patient. This collection occurs through an 80-question multiple choice survey that asks about:

- individual's physical and mental health (ex. diagnosis, discharge disposition);
- frequency of visits to physician or hospital;
- health services provided, speed at which they were provided and the tests administered;
- whether tissue or bodily samples were taken for testing or examination;
- whether drugs were prescribed;
- whether health care aids, devices or products were prescribed;
- level of education, ethnic origin, type of residence and language spoken; and
- personal view or opinions about the issue or facility being surveyed.

[16] I have reviewed the information disclosed by regional health authorities and collected by the HQCA, and find it is health information. I also find the HQCA collects some personal information directly from the patient.

### Analysis of Issues

#### **Issue 1 - Did the DTHR disclose the complainant's health information in contravention of Part 5, Division 1 of HIA?**

[17] The DTHR discloses health information to the HQCA. Collection of this information enables the HQCA to create a sample selection of patients to survey, and provides information to compare and analyze with information subsequently collected directly from the patient.

[18] The relevant portions of HIA that speak to disclosure of health information read:

*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,*

*36 A custodian may disclose individually identifying registration information without the consent of the individual who is the subject of the information*

*(a) for any of the purposes for which diagnostic, treatment and care information may be disclosed under section 35(1) or (4),*

*47(1) A custodian referred to in section 1(1)(f)(iii), (iv) or (vii) may request another custodian to disclose to the requesting custodian individually identifying health information for any of the purposes listed in section 27(2)*

*(a) if the requesting custodian is authorized by an enactment of Alberta or Canada to obtain the information from the other custodian,*

*(6) Individually identifying health information may be disclosed under this section without the consent of the individual who is the subject of the information.*

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

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

*27(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;*

*(d) health policy development.*

[19] The DTHR says disclosure is authorized under sections 35 and 47 of HIA. Section 35 concerns disclosure of diagnostic, treatment and care information without consent from one custodian to another for purposes listed in section 27(1)

or (2). Section 47 concerns disclosure of any type of health information without consent where one custodian requests disclosure from another custodian for any of the purposes listed in section 27(2).

[20] Section 27 sets out the purposes for which health information can be used by custodians. Section 27(1) establishes the primary uses of health information to provide health services and section 27(2) establishes the secondary uses necessary to manage the health system. This section functions as the cornerstone to the operation of the HIA, as the authorized uses of health information serve as the primary basis for establishing authority to collect and disclose health information. Generally speaking, a custodian may collect or disclose health information without consent so long as it is for one of the purposes listed in section 27.

[21] The *Regional Health Authorities Act, Health Quality Council of Alberta Regulation* (130/2006) (the HQCA Regulation) identifies the mandate of the HQCA. The mandate is instructive to the examination of the purposes for which the HQCA may use health information. Section 7(2) of the Regulation reads:

*7(2) The council will undertake the following activities in cooperation with health authorities and in accordance with an approved health plan:*

*(a) measure, monitor and assess patient safety and health service quality;*

*(b) identify effective practices and make recommendations for the improvement of patient safety and health service quality;*

*(c) assist in the implementation and evaluation of strategies designed to improve patient safety and health service quality;*

*(d) survey Albertans on their experiences and satisfaction with patient safety and health service quality.*

[22] The HQCA is tasked with assessing, identifying practices and making recommendations to improve patient safety and health service quality in Alberta. The HQCA also participates in implementing and evaluating strategies to improve patient safety and health service quality. Collection and use of health information is necessary in order to meet this mandate that is established in law.

[23] The information provided to me by the DTHR and the HQCA indicates information was disclosed by the DTHR to the HQCA to be used for some or all of the purposes listed in section 27(2) of HIA. This section, which provides authority for the secondary use of health information to manage the health system, only applies to a provincial health board, regional health authority, Alberta Cancer Board, Alberta Health and Wellness or the Minister. A physician or pharmacist, for example, is not authorized to use health information under this provision. The provision recognizes certain custodians have responsibilities within a geographic

area and need to use health information to promote the objectives they are responsible for.

[24] The HQCA is a provincial health board. The HIA authorizes a provincial health board to use health information for any of the purposes listed in section 27(1) or (2) of HIA.

[25] Section 35(1) of HIA authorizes disclosure of diagnostic, treatment and care information to a custodian authorized to use health information for section 27(1) or (2) purposes. Section 36 authorizes disclosure of registration information for any of the purposes for which diagnostic, treatment or care information may be disclosed under section 35(1) or (4). The HQCA is authorized to use health information for section 27(1) or (2) purposes. Therefore, I find the DTHR is correct in its assessment that health information may be disclosed without consent to the HQCA. Sections 35(1) and 36 authorize the DTHR to disclose diagnostic, treatment and care and registration information to the HQCA.

[26] The DTHR also said section 47 authorizes disclosure of health information without consent to the HQCA. Section 47 says a provincial health board, regional health authority or the Alberta Cancer Board may request another custodian to disclose health information for any section 27(2) purpose if the custodian is authorized to obtain the information being requested. I have already found the HQCA is a provincial health board authorized to use health information for section 27(2) purposes. Therefore, if the HQCA has authority to “obtain” or collect the health information, this provision will provide additional authority for the DTHR to disclose health information. The HQCA’s authority to collect the information at issue is examined under Issue 2.

**Issue 2 - Did the HQCA collect the complainant’s health or personal information in contravention of Part 3 of HIA and Part 2, Division 1 of FOIP?**

[27] To decide if the HQCA collected health or personal information in contravention of HIA or FOIP, I must answer the following four questions:

1. Does the HQCA have authority to collect health information?
2. Does the HQCA have authority to collect health information indirectly?
3. Was collection of health information limited to only the amount essential to carry out the intended purpose?
4. Does the HQCA have authority to collect personal information?

[28] The relevant portions of HIA and FOIP read:

*Health Information Act*

*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.*

*22(1) A custodian must collect individually identifying health information directly from the individual who is the subject of the information unless subsection (2) applies.*

*(2) A custodian may collect individually identifying health information from a person other than the individual who is the subject of the information in the following circumstances:*

*(a) where the individual who is the subject of the information authorizes collection of the information from someone else;*

*(d) where collection from the individual who is the subject of the information is not reasonably practicable;*

*(g) where disclosure of the information is authorized under Part 5.*

*(3) When collecting individually identifying health information about an individual directly from the individual, the custodian must take reasonable steps to inform the individual*

*(a) of the purpose for which the information is collected,*

*(b) of the specific legal authority for the collection, and*

*(c) of the title, business address and business telephone number of an affiliate of the custodian who can answer the individual's questions about the collection.*

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

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

*(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;*

*(d) health policy development.*

*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,*

*Freedom of Information and Protection of Privacy Act*

*33 No personal information may be collected by or for a public body unless*

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

*(b) that information is collected for the purposes of law enforcement, or*

*(c) that information relates directly to and is necessary for an operating program or activity of the public body.*

Does the HQCA have authority to collect health information?

[29] The HQCA says health information is collected under the authority of section 7(2) of the HQCA Regulation, which in turn provides authority under section 20(a) of HIA. Section 20(a) of HIA authorizes collection if it is expressly authorized under an enactment of Alberta or Canada. The HQCA Regulation is an enactment of Alberta. Therefore, collection will be authorized if section 7(2) of the HQCA Regulation expressly authorizes collection.

[30] Section 7(2) of the HQCA Regulation says, “The council will undertake the following activities in cooperation with health authorities and in accordance with an approved health plan”. Section 7(2) sets out the objectives or the mandate of the council, but does not expressly provide authority to collect health information.

[31] I also examined section 10(1) of the HQCA Regulation, which reads:

*10(1) The Council shall have reasonable access to information held by health authorities as necessary to carry out its objects related to*

*(a) collecting and analyzing information on patient safety, health service quality and significant incidents provided by Quality Assurance Committees, health authorities or other sources,*

*(b) identifying factors causing or contributing to problems with patient safety, health service quality or significant incidents,*

*(c) reviewing reports made*

*(i) by a medical examiner or other investigative body, or  
(ii) in the course of a public fatality inquiry,*

*and*

*(d) making recommendations on strategies for improving patient safety,  
health service quality and the reduction of significant incidents.*

[32] Section 10(1) of the HQCA Regulation requires a health authority to provide reasonable access to information necessary for the HQCA to carry out its mandate. Section 10(1)(a) says the HQCA shall have this reasonable access to carry out its objects related to “collecting and analyzing information ...”. The Regulation provides authority for the HQCA to access information it needs to collect to fulfill its mandate. In my view, this provides express authority to collect information, which is only limited by the word “reasonable”. This is consistent with section 58(1) of HIA that requires a custodian to only collect the amount of health information essential to carry out the intended purpose. The question of whether collection was appropriately limited is examined later in this report.

[33] I find that section 20(a) of HIA, read in conjunction with section 10(1) of the HQCA Regulation, authorizes collection of health information.

[34] Authority to collect health information can also be found in section 20(b) of HIA. It is not necessary for me to analyze whether section 20(b) authorizes collection because I have already found collection is authorized under section 20(a). However, I previously found the HQCA has authority to use health information to carry out some or all of the purposes listed in section 27. Section 20(b) authorizes a custodian to collect health information that relates directly to and is necessary to carry out these purposes. Therefore, I find section 20(b) also authorizes the HQCA to collect health information.

Does the HQCA have authority to collect health information indirectly?

[35] The HQCA says section 22(2)(g) of HIA authorizes indirect collection, which means collection from a person other than the individual who is the subject of the information. This section says health information may be collected indirectly where disclosure is authorized under Part 5. Indirect collection is authorized if any of sections 31 to 56 (Part 5) authorize disclosure of health information. I previously found that sections 35 and 36 authorize disclosure. Therefore, I find the HQCA has authority to collect health information indirectly.

Was the collection of health information limited to only the amount essential to carry out the intended purpose?

[36] Section 58(1) of HIA says a custodian must limit its collection of health information to only the amount essential to carry out the intended purpose. The HQCA says it considered what information was essential to carry out the survey’s

data analysis purposes and only requested and collected this limited data set. The HQCA did not collect all health information available from health authorities. I have reviewed the data elements collected and believe the HQCA has taken a reasonable approach in deciding what information to collect, and collected only what is essential. In my view, there is a plausible connection between the data elements collected and the purpose of the survey. I find the collection complies with section 58(1).

[37] The HQCA has completed a number of surveys since its inception. This is the first survey it completed where individually identifying health information is collected. I believe the HQCA has diligently examined the information it needs for this survey; however, a post survey review would be useful to confirm the pre-survey assessment of data elements needed. This would enable the HQCA to confirm the data elements necessary or further limit collection for future surveys as appropriate.

Does the HQCA have authority to collect personal information?

[38] The HQCA collects a limited amount of personal information for assessment purposes. This information is collected directly from the individual, and only in situations where the individual agrees to participate in the voluntary survey.

[39] Section 33(a) of FOIP says no personal information may be collected by a public body unless the collection of that information is expressly authorized by an enactment of Alberta or Canada. I have found that section 10(1) of the HQCA Regulation provides express authority to collect information necessary to carry out its mandate. I have reviewed the personal information collected by the HQCA and believe it is reasonably necessary to carry out the survey's purposes. Therefore, I find the HQCA has authority to collect personal information.

### **Issue 3 - Did the HQCA fail to safeguard health and personal information in contravention of section 60 of HIA and section 38 of FOIP?**

[40] Sections 60 of HIA and 38 of FOIP both require that reasonable steps be taken to protect health or personal information. These sections read as follows:

#### *Health Information Act*

*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.*

#### *Freedom of Information and Protection of Privacy Act*

*38 The head of a public body must protect personal information by making reasonable security arrangements against such risks as unauthorized access, collection, use, disclosure or destruction.*

[41] The HIA provides more detail in its description of required safeguards than FOIP. This does not necessarily mean HIA sets a higher standard. Both laws require that reasonable steps be taken to protect health or personal information. This means a custodian or public body must conduct an assessment of risk and ensure reasonable steps are taken to mitigate a risk that is identified. For a custodian, implementing a new project or system or making changes to an existing project or system requires a privacy impact assessment (PIA) to be submitted to the Commissioner for review and comment prior to implementation. A PIA is an effective tool to examine risk and consider implementation of safeguards to mitigate risk. FOIP does not require a public body to submit a PIA, but a PIA is recommended as a best practice and may be required by the Commissioner in some cases.

[42] The HQCA was required by section 64 of the HIA to submit a privacy impact assessment (PIA) to the Commissioner for review and comment before this project was implemented. The HQCA submitted a PIA on February 7, 2007, which was prior to implementation of the survey. The PIA was assigned to a Portfolio Officer

on the Commissioner's health team. Review of the PIA found there were some areas that required clarification. The HQCA quickly and thoroughly addressed these areas and the PIA was accepted on May 15, 2007.

[43] The steps taken by the HQCA to maintain safeguards to protect health and personal information, most of which are outlined in the PIA submission, include:

- Established organizational privacy and security policies and procedures;
- Assessed and took reasonable steps to mitigate risk related to transmission and storage of the information;
- Limited collection, use and disclosure of the information to only what was essential to carry out the intended purpose;
- Controlled access to survey data;
- HQCA staff sign confidentiality oaths and have received privacy training
- The agreement with Prairie Research Associates (PRA) contains appropriate privacy and security clauses;
- HQCA took reasonable steps to ensure PRA has appropriate privacy and security policies in place, including a teleconference to discuss how survey information would be safeguarded while in the custody of PRA;
- PRA employees must sign and acknowledge they have read PRA's privacy policies and received privacy training, and those employees conducting the interview must also sign a confidentiality agreement; and
- The survey information collected by PRA is returned to the HQCA and PRA is required to send the HQCA a formal notification of the secure destruction of any respondent health or personal information upon conclusion of the survey.

[44] I have reviewed the steps taken by the HQCA that are described in the PIA, and additional correspondence provided to me. This review includes examining the agreement and other steps taken by the HQCA to contract with PRA to assist with the survey. I find the HQCA took reasonable steps to protect health and personal information, and complied with sections 60 of HIA and 38 of FOIP.

## **V Conclusion**

[45] I have found the David Thompson Health Region has authority to disclose health information to the Health Quality Council of Alberta (HQCA), and the HQCA has authority to collect health and personal information. I have also found the HQCA has taken reasonable steps to protect health and personal information.

[46] I believe the HQCA provides a positive example to other custodians about how to properly implement a new system or project. The HQCA met with our Office to discuss its role as a custodian and examine HIA implications to their operations. It sought early advice on completing a PIA for this survey and did so before implementation. Questions asked during review of the PIA were quickly and thoroughly answered. Acceptance of a PIA does not compromise the Commissioner's ability to independently review this or any other complaint;

however, when these due diligence steps are taken, it is not surprising that the investigation finds the project fully complies with the law.

[47] The HQCA has committed to amending its PIA for each additional survey it conducts involving health information. Our Office will review these amendments to ensure the HQCA continues to diligently assess its authority to collect and use health information, and takes necessary steps to protect it. This provides reasonable assurance that future surveys will also comply with HIA.

Submitted by

LeRoy Brower  
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