



INVESTIGATION REPORT 02-01

INVESTIGATION OF A PATIENT SURVEY BY THE CHILDREN'S AND WOMEN'S HEALTH CENTRE OF BRITISH COLUMBIA

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1.0 INTRODUCTION

[1] In 2000, the Children's and Women's Health Centre of British Columbia ("Health Centre") carried out a survey of parents of pediatric patients and their families to obtain their views on services the Health Centre provides. The Health Centre is a public body under the *Freedom of Information and Protection of Privacy Act* ("Act") and must, therefore, comply with the privacy provisions in Part 3 of the Act. The Office of the Information and Privacy Commissioner ("OIPC") has the authority under s. 42 to conduct investigations to ensure compliance with the Act. The OIPC decided to investigate the survey to ensure that it complied with Part 3. Our investigation looked at collection of personal information under s. 26 of the Act, use of personal information under s. 32 and disclosure of personal information under s. 33 of the Act.

[2] The relevant parts of the Act read as follows:

Purpose for which personal information may be collected

- 26 No personal information may be collected by or for a public body unless
- (a) the collection of that information is expressly authorized by or under an Act,
 - (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.

How personal information is to be collected

- 27(1) A public body must collect personal information directly from the individual the information is about unless
- (a) another method of collection is authorized by
 - (i) that individual,
 - (ii) the commissioner under section 42(1)(i), or
 - (iii) another enactment,
 - ...
- (2) A public body must tell an individual from whom it collects personal information
- (a) the purpose for collecting it,
 - (b) the legal authority for collecting it, and
 - (c) the title, business address and business telephone number of an officer or employee of the public body who can answer the individual's questions about the collection. ...

Protection of personal information

- 30 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 disposal.

Retention of personal information

- 31 If a public body uses an individual's personal information to make a decision that directly affects the individual, the public body must retain that information for at least one year after using it so that the individual has a reasonable opportunity to obtain access to it.

Use of personal information

- 32 A public body may use personal information only
- (a) for the purpose for which that information was obtained or compiled, or for a use consistent with that purpose (see section 34),
 - (b) if the individual the information is about has identified the information and has consented, in the prescribed manner, to the use, or

Disclosure of personal information

- 33 A public body may disclose personal information only
- ...
- (b) if the individual the information is about has identified the information and consented, in the prescribed manner, to its disclosure,
 - (c) for the purpose for which it was obtained or compiled or for a use consistent with that purpose (see section 34),

Definition of consistent purposes

- 34 (1) A use of personal information is consistent under section 32 or 33 with the purposes for which the information was obtained or compiled if the use
- (a) has a reasonable and direct connection to that purpose, and
 - (b) is necessary for performing the statutory duties of, or for operating a legally authorized program of, the public body that uses or discloses the information...

General powers of commissioner

- 42 (1) In addition to the commissioner's powers and duties under Part 5 with respect to reviews, the commissioner is generally responsible for monitoring how this Act is administered to ensure that its purposes are achieved, and may
- (a) conduct investigations and audits to ensure compliance with any provision of this Act,
 - (b) make an order described in section 58 (3) whether or not a review is requested,

2.0 BACKGROUND

[3] The OIPC first learned of the survey when the Health Centre requested advice on the amount and types of personal information it intended to disclose to a contractor, in the form of a patient list, so that the contractor could conduct a patient satisfaction survey as part of what the Health Centre described as its quality assurance activities. The agency hired to carry out the survey was the Picker Institute, Inc. ("Picker Institute"), based in Boston, Massachusetts.

[4] The Picker Institute's survey guidelines listed the patient information that it wished the Health Centre to supply to it electronically. They included, amongst other things, name, age, gender, address, diagnosis, procedure, medical record number, admission, discharge date and discharge services detail. It appeared the Picker Institute was using a standard type of software and the range of personal information required for the running of the program seemed to exceed acceptable disclosure under s. 33 of the Act. For example, the "diagnosis code" and "phone number" were not required fields, but the Picker Institute recommended that the Health Centre provide this information.

[5] The OIPC reviewed the elements of personal information that the Picker Institute stated it required in order to conduct the survey and which the Health Centre proposed to disclose for that purpose. The OIPC expressed some concerns about the proposed disclosure and made recommendations for changes to the amount and type of personal information to be disclosed. The OIPC recommended that the disclosure of information for the survey be consistent with the fair information practices articulated in Part 3 of the Act and that the Health Centre only disclose minimal personal information that related directly to and was necessary in order to conduct the survey.

[6] The OIPC also recommended that the proposed contract address collection, security, retention, access, use and disposal of the personal information and that any person working on the project have proper training in these areas and clearly understand and agree to abide by Part 3 of the Act. Further, the OIPC recommended that the Health Centre retain the right to audit the contract for compliance with the Act.

[7] The OIPC also recommended that the Health Centre comply with s. 27 of the Act and ensure that patients are informed of the purpose and the legal authority for the contractor collecting their personal information in a survey, when patients are filling out admission

forms and that they be given the option of “opting-out” if they so choose. The OIPC also stressed the importance of informing all survey respondents that their participation is voluntary.

[8] The OIPC sent a letter to the Health Centre with these comments and recommendations, with a request that the Health Centre keep us abreast of the progress of this project.

[9] The survey next came to the attention of the OIPC through parents who had been contacted by the Picker Institute’s subsidiary, the CarePointe Research Center (“CarePointe”), based in Georgia, following their child’s admission to the Health Centre. The parents expressed concern that the Health Centre had apparently disclosed their and their child’s names to an American company, without their knowledge and consent. The parents supplied us with the survey and its covering letter from the Health Centre. The 81 survey questions asked parents their views on areas such as emergency and admission procedures, doctors, nurses and the care their children had received (including pain management while in intensive care). The survey also asked parents to provide information on the child’s and parents’ background.

[10] The OIPC then decided to conduct an investigation of the circumstances surrounding the survey, to verify that the Health Centre had complied with Part 3 of the Act.

3.0 ISSUES INVESTIGATED

[11] The OIPC investigated the following issues:

- the purpose of the survey;
- the legal authority for conducting the survey;
- the kind of consent collected and notification provided;
- what information had already been disclosed to, and might be disclosed to, the Picker Institute and the CarePointe Research Center;
- what uses would be made of the personal information and what would happen with the results of survey analysis;
- what would happen to the surveys themselves;
- whether there would be other uses or disclosures of the information, either by the Health Centre or the two outside bodies, either in identifiable or anonymized form, and for what purpose; and
- whether there would be any future surveys of this type.

[12] The OIPC also inquired about the questionnaire itself, as the questions appeared to be generic and not designed exclusively for the Health Centre. Not all the questions seemed to be relevant to the issue of care provided by the Health Centre, in particular questions which dealt with the parents’ age, education and so on. Thus, the OIPC asked if the survey

was requesting personal information that CarePointe (and, by extension, the Health Centre) did not need.

[13] The OIPC also asked about the physical security arrangements that the contractors provided for the personal information they collected; what confidentiality requirements these two bodies imposed on their employees; how the survey company linked the completed surveys with the Health Centre; how it ensured that the respondents' names were not connected with the results; and how it compiled the survey results and in what form it provided those results to the Health Centre.

[14] During the investigation the issue of trans-border flows of personal information also arose, in light of the fact that the survey contractor is located in the United States.

[15] The OIPC also followed up on our earlier recommendations on disclosure of patient lists to the survey contractor, as the OIPC had not received any updates from the Health Centre since the OIPC's first letter.

4.0 HEALTH CENTRE'S RESPONSES

[16] The Health Centre's responses to the OIPC's enquiries follow.

[17] **4.1 Disclosure of Patient Lists** – The Health Centre said that, upon receipt of the OIPC's initial letter of recommendations and comments on disclosure of patient lists, it had made the changes it felt were necessary to comply with the Act, as follows:

- The OIPC had said that the range of personal information the field descriptions listed exceeded what is acceptable disclosure under s. 33 of the Act, as the purpose of the information was to benefit the Health Centre's ability to further analyze the data by stratifying it by diagnosis and procedures, as it receives the data file back with the survey results.

The Health Centre's opinion was that the information disclosed relates directly to and is necessary for its quality assurance activities.

- The OIPC had said that some of the fields proposed for disclosure, such as those related to diagnosis and procedure, were noted in the guidelines as optional and were therefore not necessary for the conducting of the survey.

The Health Centre told us that these fields were dropped from the information provided to the Picker Institute in order to comply with s. 33 of the Act.

- The OIPC had noted that "phone numbers" were one of the optional fields.

The Health Centre said that this field was for the benefit of the hospital if it wished to follow-up with some of the parents' comments if parents requested a follow-up. The

Health Centre said it decided not to use this survey option and therefore did not release parents' phone numbers.

- The OIPC had recommended that the Health Centre inform parents, at the time their children were admitted, that they might be contacted later to participate in a follow-up survey and that the parents be asked for their permission for such contact. The OIPC also recommended that parents be told that participation in the survey would be voluntary.

The Health Centre did not expressly follow these recommendations in that it adopted an oral process for collecting consent. The OIPC discusses these points further below.

[18] **4.2 The Survey** – A number of issues arose regarding the survey.

Legal authority for the collection

[19] The OIPC requested information on the Health Centre's legal authority to conduct the survey. In response, the Health Centre stated that, while there is no statutory authority that specifically authorizes the Health Centre to carry out surveys in particular, in its view, these activities are an appropriate facet of its quality assurance activities and contemplated by statute, as cited below:

Hospital Act

Requirements for hospitals

2(1) A hospital, except a hospital owned by the government or by Canada, must do the following:

...

- (c) have a properly constituted board of management and bylaws or rules thought necessary by the minister for the administration and management of the hospital's affairs and the provision of a high standard of care and treatment for patients;

....

2(2) The constitution and bylaws or rules of a hospital, including medical staff bylaws, are not effective until approved by the minister.

Certain actions for damages prohibited

41(1) In this section, "medical staff committee" means a committee established or approved by a board of management of a hospital for

- (a) evaluating, controlling and reporting on clinical practice in a hospital in order to continually maintain and improve the safety and quality of patient care in the hospital, or

- (b) performing a function for the appraisal and control of the quality of patient care in the hospital.

Hospital Act Regulations

Medical staff of a hospital

- 4(3) A hospital's medical staff must comply with all of the following:

...

- (f) participate in appropriate quality improvement activities, including, without limitation, reviewing the following:
- (i) deaths occurring in the hospital;
 - (ii) statistics regarding the progress of patients in the hospital;
 - (iii) methods of treatment of patients in the hospital;
 - (iv) results of surgery performed in the hospital;
 - (v) a case when a patient's stay in the hospital is abnormally long;

....

[20] In addition, the Health Centre relied on its own bylaws and rules, which establish quality assurance processes. Moreover, under s. 26(c) of the Act, the Health Centre believes that collection of personal information for quality assurance activities relates to and is necessary for an operating program of a health facility. Such activities are also consistent, in its view, with the purpose for which the information was collected under ss. 32, 33(c) and 34(b) of the Act.

[21] The Health Centre also argued that s. 51 of the *Evidence Act* contemplates the existence of quality assurance activities within hospitals and, in fact, provides significant legislative protection to those activities and to the patients' information that may be used as part of those activities.

[22] The Health Centre informed the OIPC that the Canadian Council on Health Facilities Accreditation requires that acute care teaching hospitals, such as the Health Centre, demonstrate quality assurance activities that specifically include feedback from patients/families and patient/family survey forms are expected components.

[23] In response to the OIPC's question about the purpose of the survey, the Health Centre stated that it conducted the survey to learn about the experiences of children and family members during their stay at the Health Centre and how the Health Centre can improve the quality of care it provides, as part of the hospital's quality assurance program. The Health Centre contracted with the Picker Institute to carry out the survey, which in turn used its subsidiary, the CarePointe Research Center, to send out the survey mailings and receive completed surveys. Further, it said, the survey was developed by the Children's Medical Center of Boston in collaboration with the Picker Institute, using extensive input

from patients and families to identify the most important and relevant dimensions of the health care experience.

[24] The Health Centre said that satisfaction surveys are part of its regular quality assurance activities. It is the Health Centre's position that such surveys provide an important perspective on how it is providing service to its patients and their families.

[25] It said that the goals of the survey were twofold:

1. to understand how the needs and expectations of patients and families are being met; and
2. to understand how care is delivered within the existing system, and to understand what changes need to occur to improve the health and well being of children and youth.

[26] The OIPC is persuaded that, while there is no statutory authority that specifically authorizes the Health Centre to carry out surveys as part of its operational programs, it is appropriate, and contemplated under ss. 26, 32 and 34 of the Act and the *Hospital Act* as cited above, for the Health Centre to conduct such surveys. The OIPC does not, therefore, consider it necessary to determine if s. 51 of the *Evidence Act* applies in this case.

Survey questions

[26] The OIPC reviewed the questions and found most to be necessary and therefore appropriate collections of personal information under the Act, for example (on a random sampling from the questionnaire):

2. How well organized was the care your child received in the emergency room?
4. How well organized was the admission process?
11. When you had important questions about your child to ask the doctors, did you get answers you could understand?
15. Were the nurses available to answer your questions or concerns when you needed them?
21. Did you feel that members of the health team kept each other up to date on your child's needs?
33. Did someone explain to your child the tests that were being done in a way he or she could understand?
34. Did anyone discuss your child's fears or anxieties about the surgery or procedure with your child?
35. Were you told what activities your child could or could not do when he or she got home, such as eating, bathing, playing sports, or returning to school?
36. Overall, how would you rate the care your child received at the hospital?

71. Including this hospital stay, how many times in the last six months has your child been in a hospital overnight or longer?

[27] However, the OIPC told the Health Centre that, although the OIPC could understand why some of the questions were related to the survey purpose, the relationship of some was less clear, given that the survey was directed to individuals of 17 years of age or less. Questions 75-79 were directed at the parent or custodian of the child and requested information that the OIPC did not believe to be necessary in order to conduct the survey:

75. What year were you born?

76. Are you ... Female ... Male?

77. What is the highest grade or level of school that you completed?

78. What is your current marital status?

79. Do you usually speak English at home or some other language?

[28] On this last issue, the Health Centre responded that it strives to be family-centred in its approach to patient care. These questions provide it with some information about the families of its patients and help it to tailor its approach to better meet its patients' needs. Therefore, the Health Centre told the OIPC, demographic questions are added to the survey to allow for further analysis of the survey data.

[29] The OIPC is not convinced that these questions are necessary. The OIPC recommends that the Health Centre reconsider its use of such questions in any similar future surveys and that it administer surveys which address its particular needs rather than using off-the-shelf material. This will prevent the collection of unnecessary personal information.

Consent and Notification

[31] Section 27 of the Act requires a public body to tell an individual from whom it collects personal information the purpose for collection and the legal authority for collection. As noted above, in initial correspondence with the Health Centre, the OIPC recommended notifying patients and their families on admission that they might be contacted to take part in a survey and requested to give their written consent to such contact.

[32] When the OIPC followed up during the investigation, the Health Centre expressed concern that, by using this method, it would eliminate a category of patient and family that might have valuable information. The Health Centre took the position that it does not require consent, as the data are privileged and confidential and would be used for consistent uses only. In other words, s. 33(c) of the Act allows disclosure to its contractor, without consent, for the survey's purposes.

[33] However, the Health Centre stated that it has incorporated the OIPC's suggestion into its admission process by including a standard verbal question by admitting clerks, who

ask all patients and families whether they are willing to be contacted by the Health Centre for such purposes. This verbal response is then recorded in an electronic patient database, from which a report is generated that identifies only those who have agreed to be contacted for survey purposes. The OIPC would prefer to see such consent and notification recorded on a signed admission form, rather than taken verbally.

Voluntary participation and opting-out

[34] The OIPC also recommended, during the initial consultation with the Health Centre, that the survey materials stress that participation is voluntary. The OIPC followed up on this issue during the investigation. The OIPC found that this information did not appear to be on the admissions form. In addition, while a follow-up letter from the survey company covered this issue, the initial covering letter did not state this clearly. Further, it was not clear that patients were told at the time of admission or in the survey letters that they could opt out from being contacted for follow-up surveys.

[35] The Health Centre stated that the omission of informing respondents on the cover letter that their participation in the survey is voluntary was an oversight. It will ensure that this information is included in the cover letter for any future surveys.

[36] The OIPC would also like admissions forms to make it clear that patients' participation in surveys is voluntary and that patients have the right to opt out of any follow-up surveys.

Trans-border data flows

[37] Acknowledging the Health Centre's decision that the Picker Institute was the best company for the project, the OIPC notes that, when personal information is transmitted, used and stored outside Canada, protection under Canada's relatively uniform privacy laws is lost. Since the Health Centre remains liable for compliance with Part 3 of the Act even where it has contracted out services as in this case, the Health Centre in all such cases should ensure contractors implement the Act's privacy provisions rigorously, as the Health Centre remains responsible for compliance with Part 3. This is illustrated by Investigation Report 01-01, which can be found at: www.oipc.bc.ca/investigations/reports/IR01-01.pdf.

Information already disclosed

[38] At the time the OIPC received the parents' complaint regarding this survey, the CarePointe Research Center had obviously already sent out the initial letter and survey to parents. This suggested that the Health Centre had already disclosed at least some patient information to enable CarePointe to select respondents' names randomly and send them the letter and survey. The OIPC asked the Health Centre what information it had disclosed to the Picker Institute for this purpose.

[39] The Health Centre responded that the data fields which it shared with the Picker Institute for these purposes were:

- child's first and last name
- medical record number (a unique patient identifier)
- admission date and discharge date
- discharge service (i.e., only those discharged to home; discharged with M-medicine or S-surgery)
- age
- gender
- address, city, postal code

[40] As stated earlier, the OIPC had previously reviewed and made recommendations regarding the data (patient lists) to be disclosed to the survey company, which resulted in the above pared-down version.

Legal authority to disclose information to the Picker Institute

[41] The OIPC also inquired about the Health Centre's legal authority to disclose information to the Picker Institute. It appeared that the Health Centre had not obtained parents' or patients' consent prior to disclosing the patient information to the Picker Institution or the CarePointe Research Center.

[42] However, as discussed above under the section on legal authority for doing surveys, the OIPC found that the Health Centre's survey, as part of its operational activities, related to and was necessary for an operating program of a health facility under s. 26(c) of the Act. Further, public bodies covered by the Act also have the authority under s. 33 to disclose personal information under a number of limited circumstances. Section 34 sets out the definition of consistent purposes. The OIPC therefore considers that ss. 33(c) and 34(1)(a) and (b) of the Act allowed the Health Centre to disclose information to the Picker Institute without consent. However, the OIPC believes it is preferable to obtain consent in such circumstances and so recommends to the Health Centre for the future.

Physical security

[44] The OIPC inquired about the physical security arrangements that the Picker Institute and CarePointe Research Center provide for the personal information they collected from the Health Centre.

[45] The OIPC was told that all patient lists and survey data received by both the Picker Institute and the CarePointe Research Center are kept on secure computer file-servers that cannot be accessed by anyone not involved in the project. Patient lists are destroyed at the end of each project and survey data files are processed without patient-identifying information.

[46] The OIPC considers that the Health Centre, through its contractor, has provided for sufficient security in this area and that it therefore meets s. 30 standards.

Confidentiality

[47] The OIPC also wanted to know what confidentiality requirements the Picker Institute and the CarePointe Research Center impose on their employees to ensure the safety of the information they collect.

[48] The Health Centre informed us that all employees of the Picker Institute and the CarePointe Research Center are required to sign strict confidentiality agreements. Patient names are never discussed. The OIPC found this to be satisfactory.

Results of the survey

[49] The covering letter of the survey assures respondents that their names will not be connected with the results. The OIPC asked how the survey company would accomplish this. Specifically, the OIPC asked if the Picker Institute removed all patient-identifying information from the survey data. The Health Centre informed us that the Picker Institute removes all such information, aggregates it at the Health Centre level and adds it to the Health Centre's comparative database.

[50] The OIPC was told that each survey contains a unique numerical identifier that maps back to a specific patient record and hospital experience. Data files are processed with that unique identifier, as a substitute for using any specific patient name. In addition, survey results are always reported in aggregate, using the unique numerical identifiers. Actual patient names are never attached to any survey data.

[51] The Health Centre explained that the aggregate reports that it receives from the Picker Institute would be circulated to the Health Centre's Child Health Quality of Care Committee and used as part of the quality-monitoring system to identify areas for improvement of patient care process. The OIPC was satisfied with the handling of the results of the survey on the basis that no identifying personal information is connected to the results of the survey.

Disposal of the surveys

[52] When the OIPC asked how the contractor disposes of the surveys once they are completed, the Health Centre informed us that, after receipt and tabulation of completed surveys, CarePointe Research Center shreds the surveys and that it destroys the patient lists after one year. The OIPC is satisfied that the survey materials are being disposed of appropriately under s. 30 of the Act.

Other uses and disclosures of the information

[53] The Health Centre informed us that the only disclosure of information is in aggregate form in a report back to the Health Centre itself for its own use. It plans no further use or disclosure of the data other than addressed above. Section 32 is thus not an issue.

Future surveys

[54] The OIPC asked if the Health Centre will carry out similar surveys in the future. The Health Centre responded that it considers this initial survey to be a pilot project. Once the report was received, the Health Centre would be evaluating the usefulness of the process and the information provided. The Health Centre stated that one of the benefits of this type of survey is to monitor results over time and measure whether changes to the care delivery process are actually resulting in improvements in the eyes of its customers. However, it said it currently had no plans to conduct any similar survey.

Contract

[55] The contract with the Picker Institute contains very specific language related to confidentiality of clients' data and reports containing such data and non-disclosure, either directly or indirectly, to any third party. It also specifically states that the reports will not contain any patient-specific information.

[56] The OIPC agrees that the Health Centre and the Picker Institute have addressed the issue of confidentiality in its agreement. However, the contract should contain wording consistent with the language of the Act. In future, the Health Centre should ensure that any such contracts address collection, security, retention, access, use and disposal and that any person working on these projects has proper training in these areas and clearly understands their legislative responsibilities articulated in Part 3 of the Act.

[57] In the initial consultation, the OIPC also recommended that the Health Centre retain the right to audit the contract for compliance during our initial consultation. The Health Centre acknowledged that the contract did not specifically address this issue. It was the Health Centre's opinion that the terms of the contract would allow for such an audit to take place. As a result of this investigation, the Health Centre now acknowledges that the inclusion in the contract of terms that specifically addressed the audit issue might have been preferable. The Health Centre will ensure that specific conditions are included in any future contracts of this type.

5.0 CONCLUSION

[58] The OIPC is generally satisfied with the Health Centre's responses, although the OIPC believes it could tighten-up contractual language and practices in some areas, as noted above. To assist the Health Centre in any future contracting out of services involving personal information, the OIPC incorporates into this report, by reference, the OIPC's

Guidelines for Data Services Contracts (OIPC Guideline 01-02) and Investigation Report 01-01, both available at www.oipc.bc.ca.

6.0 SUMMARY OF RECOMMENDATIONS

[59] To summarize, the OIPC's recommendations are that:

- the Health Centre only disclose to the survey contractor minimal personal information that related directly to and was necessary in order to conduct the survey;
- the contract address collection, security, retention, access, use and disposal of the personal information;
- any person working on the project have proper training in fair information practices and clearly understand and agree to abide by Part 3 of the Act;
- the Health Centre retain the right to audit the contract for compliance with the Act;
- the Health Centre comply with s. 27 of the Act and ensure that patients are informed of the purpose and the legal authority for collecting their personal information in a survey, when filling out admission forms, that participation is voluntary and that they may "opt out" if they so choose;
- the Health Centre record consent for disclosure and notification on the signed admission form, rather than take it verbally; and
- the Health Centre reconsider its use of questions such as # 75-79 in any similar future surveys and that it administer surveys which address its particular needs rather than using generic software.

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Investigation Report written by Celia Francis and Judy Durrance.

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