



OFFICE OF THE
INFORMATION & PRIVACY
COMMISSIONER
— for —
British Columbia

INVESTIGATION REPORT 01-02

INVESTIGATION INTO CANADIAN YOUTH, SEXUAL HEALTH & HIV/AIDS STUDY 2001

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1.0 PURPOSE OF THIS DOCUMENT

[1] This document sets out the findings of fact, and resulting recommendations, of the Information and Privacy Commissioner for British Columbia (“Commissioner”), regarding the Canadian Youth, Sexual Health & HIV/AIDS Study 2001 (“study”) and its compliance with the privacy provisions of the *Freedom of Information and Protection of Privacy Act* (“Act”).

[2] It should be said at once that the Office of the Information and Privacy Commissioner for British Columbia (“OIPC”) strongly supports properly conducted social science research in schools. Research can benefit the education, health and welfare of Canadian youth and adults. The only issue of interest to the OIPC is whether academic research, including this study, is conducted in accordance with the Act, which applies to school districts, universities and colleges that collect “personal information” from students. The questions asked in the study – many of which delve into sensitive matters about drug or alcohol use and sexual practices and experiences – are *not* the reason for this investigation. That aspect of the study is outside the OIPC’s mandate. Having said that, whenever research involves collection of such sensitive information, it is especially important to determine whether “personal information” is being collected and, if so, to ensure the Act’s privacy provisions are complied with.

2.0 BACKGROUND

[3] The study is being conducted across Canada by a consortium of researchers from the University of Alberta, Acadia University, Queen’s University and Laval University.

[4] According to the researchers, the study is intended to gather

... students' knowledge, attitudes, and behaviours with respect to HIV/AIDS and other sexually transmitted diseases so that educators and health service professionals can design programs and services that will help young people protect themselves.

[5] The study is intended to “examine the factors associated with youth sexual health, especially with regard to HIV prevention.” The study is co-ordinated by the Council of Ministers of Education of Canada (“CMEC”) in collaboration with the HIV/AIDS Prevention and Community Action Program of Health Canada. The study has two versions. Grade 7 students in randomly selected schools across Canada will be asked to participate by answering one version of the study questionnaire. Students in Grades 9 and 11 in randomly selected schools will be asked to answer another, more detailed and longer, questionnaire for the study.

[6] Among other things, the Grade 7 version of the study questionnaire asks questions about: the student's family situation (including whether one or more parents are unemployed); religion, medical conditions such as cerebral palsy, diabetes or epilepsy; use of drugs or alcohol; perceptions of the students' attractiveness and weight; knowledge about the availability of condoms; sources of information about HIV/AIDS and other sexually transmitted diseases; and experience with sex.

[7] The questionnaire for Grades 9 and 11 delves more deeply into the sexual knowledge, attitudes and practices of youth. In addition to seeking demographic information of the kind sought in the Grade 7 version, the study asks: whether the student is attracted to one or both sexes; whether the student has recently sought medical attention for birth control, pregnancy or a sexually transmitted disease (including HIV/AIDS); knowledge about sources of condoms; knowledge about sex and sexually transmitted diseases; sexual experiences (including sexual intercourse, oral sex or other kinds of sex); whether the student has ever been forced to have sex; and how old the student was when he or she first had sexual intercourse and why they did so.

[8] The researchers describe several benefits from the study. On p. 1 of the study summary provided to school districts, it is said the study will:

1. increase understanding of the factors that contribute to the sexual health of youth;
2. provide current information to monitor youth sexual health and to inform health education and health service programs;
3. bring provincial/territorial and national attention to the need for effective sexual health education, adolescent preventative health services, and community, parents and youth-based HIV prevention programs;

4. contribute to collaboration between health service professionals and educators both within and outside of schools in the development of sexual health and HIV prevention programs and services.

[9] The products of the study that are identified by the researchers – again taken from the summary given to school districts – are as follows:

1. A national report presenting the relationships between health determinants, sexuality variables, and sexual health.
2. Individual provincial/territorial reports that compare a given province/territory's findings with the national findings will be prepared.
3. Media release of both national and provincial/territorial findings.
4. Presentations of the national findings to federal government departments and CMEC will be made by research team members.
5. Conference presentations will be undertaken by the research team across North America.
6. Publications for peer-reviewed journals, and possibly book chapters, will be prepared by the research team.

[10] Upon opening this investigation, I notified all British Columbia school districts about the investigation. I also asked school districts to tell me if they have agreed to participate. Of the school districts that responded, the following indicated they have agreed to participate (in several cases, subject to the outcome of this investigation): School Districts Nos. 28, 5, 68, 59, 83 and 62.

3.0 JURISDICTION

[11] Part 3 of the Act imposes on public bodies – which include school districts created under the *School Act* – rules regarding collection, use and disclosure of “personal information”. Under s. 42(1)(a) of the Act, the Commissioner is authorized, whether or not a complaint has been made, to conduct investigations and audits to ensure compliance with any provision of the Act including those in Part 3. If the Commissioner determines that a public body has not complied with the Act, he or she is empowered to order the public body to comply.

4.0 PROCESS FOLLOWED

[12] I became aware of the study through media reports on September 13 and 14, 2001. I contacted one of the school districts that had indicated it would participate and obtained some of the study-related materials. (The researchers had not yet provided that school district with all of the materials.) I then contacted one of the principal study researchers, Dr. Maryanne Doherty, of the University of Alberta. She provided me with further information and couriered to me a full package of the study-related material.

5.0 CONCLUSIONS

[13] The following discussion sets out the facts relevant to the OIPC's investigation. The facts were ascertained from study materials provided to the OIPC by one of the participating school districts and from my discussion with Dr. Doherty. A draft of the factual findings was twice provided to Dr. Doherty for comment or correction and she commented.

[14] **5.1 Relevant Facts** – The study, which is being conducted across Canada, will be administered in selected British Columbia classrooms. Potentially participating schools are selected through a systematic, stratified sampling method using a single stage cluster design. Each school board within which potential participating schools have been identified is approached and asked for the school district's agreement to participate. Participating school districts are asked to provide contact details for the principal at each participating school.

[15] The principal is then contacted and receives materials. The principal is asked, using methods supplied by the researchers, to randomly select only the numbers and class in each designated grade. The principal then notifies the researchers what classes have been selected. The principal is given a Parent/Guardian Information Page, which includes a parental consent form, to give to each student. The principal also receives one copy of each version of the study questionnaire, "to share with those guardians and/or parents who request to review it (them)." The principal is also invited to direct any questions or comments from parents or guardians to the researchers.

[16] The version of the parental consent form provided to the OIPC describes the purpose of the study, tells parents who is conducting it and tells them it is co-ordinated by the CMEC. It says the "study is important" and asks for support by consenting to participation. The form contains the following:

There will be no risks involved for students who participate in this study.
Participation will be voluntary and responses will be kept confidential.
Participation will not affect your son/daughter's evaluation by the school and students may withdraw at any time during the study without prejudice.

We would like to include your son or daughter in the study. Please complete the attached consent form and have your son or daughter return it to the school tomorrow.

[17] The consent portion of the consent form contains the following:

I understand that:

- all information gathered will be treated confidentially
- my child will not be identifiable in any documents resulting from this research
- my child may choose not to respond to any question and/or withdraw from the study at any time without penalty.

I also understand that this study is being conducted in accordance with the provincial Freedom of Information and Protection of Privacy Act and the information will be used for written reports and presentations.

[18] The principal is asked to provide the researchers with contact particulars for the teachers responsible for the identified classrooms. Those teachers are contacted and a package of materials is sent to them. The package includes instructions on how to administer the study. Each teacher is asked to tell students in his or her class the following (which appears in the draft instructions to teachers supplied to the OIPC):

4. Ask the students to take a copy of the memo to their parents and return the signed permission slip to you as soon as possible. Please remind the students each day so that all permission slips are returned before you administer the survey.
5. On the day of survey administration, please be conscious of the need for students to have a sense of privacy while completing the questionnaires. If a student raises his or her hand for help, deal with the question quietly. As much as possible, avoid circulating throughout the classroom.
6. Please seat students so as to maximize their privacy and inform students of the importance of respecting the privacy of others.

[19] The teacher is given a script to use in introducing the study to students, before they begin the study. They are told that participation “is voluntary” and that they have the “right to withdraw from completing the questionnaire” at any time. They are asked to answer questions alone and try not to get help from the teacher. They are also told to ask the teacher if they do not understand a word and *not* to “leave a question blank”. Last, they are told the following:

Do not write your name on the questionnaire; the information you give us is to be anonymous.

The study form also tells students not to write their name on the form.

[20] Students are given an envelope in which to place their completed study forms. When a student has completed the study, he or she places the form in the envelope provided by the teacher and seals it before handing it to the teacher. The teacher collects each sealed envelope, but does not place the student’s name, student number or other unique identifier of any kind on the sealed envelope. No attempt is made at any time to link study forms or sealed envelopes with consent forms or students. No link between students who decline to answer one or more questions and their incomplete study form is ever made.

[21] The teacher is instructed to return all of the sealed envelopes to the principal’s office in, if possible in the same padded envelope in which they arrived. The school then sends the envelopes by prepaid courier to Queen’s University, in Ontario, which is one of the participating institutions. After they are received at Queen’s University, the data in completed study forms are entered into a computer system. All completed study forms

are kept in locked filing cabinets at Queen’s University. Forms collected from British Columbia schools will be retained for seven years, according to Alberta’s ethics requirements, and will then be destroyed.

[22] The information gathered through the study is not disclosed in any form – as raw data or through published reports or journal articles – that identifies individual school districts or individual students. The data are aggregated at the provincial and national levels only.

[23] **5.2 Findings** – Based on the information provided to me by the study principals, I have concluded that the study does not involve collection of “personal information” within the meaning of the Act. This is because the information that is collected is not about an “identifiable individual”. Because “personal information” is not being collected, the Act does not apply to the study. I propose to inform all school districts in British Columbia of this finding and to inform them that I have no objection, under the Act, to the study.

[24] A number of points must, however, be made about the circumstances leading to this finding. First, there may be cases where a student could be identified from her or his answers. The study is being conducted in some fairly small communities in British Columbia. Students are asked to provide some quite detailed demographic information which, together with publicly available information, could possibly be used to identify a student. All of the rules surrounding the study, notably respecting its administration by the teacher, are designed to ensure students are not identified. I am also satisfied that the researchers will not attempt to identify any student using public information and the student’s answers. The researchers should be sure to admonish teachers, however, that they must not, for their own purposes, attempt to link students with study questionnaires. If it were to turn out that a student was or had been linked to his or her questionnaire, I would have the jurisdiction to investigate the matter further.

[25] Second, it is far from clear on the face of the study-related materials that “personal information” within the meaning of the Act is *not* being collected. On the one hand, both the direction to students in the study questionnaire and the instructions given to and by teachers indicate that the information is anonymous. On the other hand, the consent form and background information given to parents can reasonably be interpreted as indicating that information about identifiable individuals is being collected. I refer in this respect to statements in the consent form to information gathered being “treated confidentially” and the fact that a student “will not be identifiable in any documents resulting from this research”. There is no need to refer to information being “treated confidentially” unless the information is about an identifiable individual. Similarly, there is no need to assure parents that their child will not “be identifiable in any documents resulting from this research” if the child is not identifiable, in the first place, from the study questionnaire or otherwise.

[26] The consent form also refers – on what basis is not clear – to the fact that the study complies with the “provincial Freedom of Information and Protection of Privacy Act”, which of course only applies to recorded information about identifiable

individuals. The explanation in the background information for the consent form to the fact that “responses will be kept confidential”, and that there are no risks, further supports the conclusion that information collected during the study might be personal information within the meaning of the Act.

[27] It is only with the clarification provided by the background materials, and through discussions with one of the principal researchers, that it became clear that “personal information” within the meaning of the Act is not being collected. An appropriate recommendation regarding this point is made below.

[28] Second, as to the assertion in the materials that the study is “in accordance with the provincial Freedom of Information and Protection of Privacy Act”, none of the study-related material supports this statement. Nor does the study proposal that was apparently submitted for approval address this issue. Aside from the fact that it is not clear on what basis the researchers felt able to claim compliance with provincial freedom of information and privacy protection legislation across the country, the absence of any justification or supporting argument in any of the study-related materials understandably would leave school districts and others in some doubt as to the study’s compliance with privacy legislation or practices.

[29] I have already noted that, based on my discussions with one of the researchers and an indication in the study material, the study does comply with the British Columbia legislation, at least because it collects anonymous and not identifiable information. In my view, that is something that should have been clear on the face of the study materials, notably in the portions seeking school district participation. Again, each school district is a separate public body under the Act and is responsible for compliance with the privacy provisions of the Act. It would be preferable for this issue to be dealt with clearly and unambiguously at the time the school district is approached. Such clarity would certainly improve the prospect that a school district would agree to participate.

6.0 RECOMMENDATIONS

[30] Such appropriate background information should, first, include a statement (and supporting reasons) that “personal information” within the meaning of the Act is not being collected, used or disclosed as part of the proposed research. If “personal information” is to be collected, used or disclosed, researchers should clearly describe the purposes for the collection and all proposed uses or disclosures of the personal information. They should also clearly describe the security and other measures to be taken to limit collection, use and disclosure to those described circumstances and to ensure that the personal information is otherwise kept confidential and secure. It will, of course, remain for individual educational bodies to satisfy themselves that they have the authority under Part 3 of the Act to participate in the research in each case and that their obligations under s. 30 of the Act to take reasonable measures to guard against unauthorized collection, use, disclosure or disposal of personal information have been met.

[31] Again, the Act does not apply to this study. But there will be cases where information about identifiable individuals is being collected. The OIPC therefore will develop – in consultation with appropriate stakeholders such as the B.C. School Trustees Association – a set of guidelines and standard research agreements to be followed by school districts (and other educational bodies) when they are approached by researchers with a request to participate in research that involves personal information. A number of British Columbia school districts already have their own guidelines, and standard research agreements, to deal with these situations, *e.g.*, the Vancouver School District, Greater Victoria School District and the Nanaimo School District. The OIPC's intent is not to supplant already-existing school district policies or guidelines, but to offer model policies, guidelines and research agreements on our website in order to assist educational bodies in complying with the Act in a timely manner while supporting properly conducted research.

[32] I also propose to approach my colleagues in other provinces and territories, and my federal colleague, with a view to initiating a set of guidelines and supporting materials to ensure privacy compliance in federally-funded research in Canadian schools, universities and colleges.

September 18, 2001

David Loukidelis
Information and Privacy Commissioner
for British Columbia