



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

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## AUTHORIZATION FOR INDIRECT COLLECTION OF PERSONAL INFORMATION

### Ministry of Health

Elizabeth Denham, Information and Privacy Commissioner

March 30, 2012

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#### **SUMMARY**

Under s. 42(1)(i) of the *Freedom of Information and Protection of Privacy Act* ("FIPPA"), the Commissioner authorizes the BC Transplant Society, Health Authorities, Vancouver General Hospital, St Paul's Hospital, the BC Children's Hospital and the BC Renal Agency to indirectly collect personal information relating to donors and recipients located outside of British Columbia for the purposes of organ and tissue donation and transplantation from two national donor registries operated by Canadian Blood Services (the National Organ Waitlist and the Highly Sensitized Kidney Patients registry).

#### **BACKGROUND**

Section 27 of FIPPA requires that public bodies collect personal information directly from the individual the information is about, with specific exceptions. Section 42(1)(i) of FIPPA gives the Commissioner the authority to permit public bodies to collect personal information from other sources. On March 16, 2012, the Office of the Information and Privacy Commissioner received an application from the Ministry of Health for an authorization to collect personal information under s. 42(1)(i) of FIPPA. The Ministry applied on behalf of the BC Transplant Society, Health Authorities, Vancouver General Hospital, St Paul's Hospital, BC Children's Hospital and the BC Renal Agency. All are public bodies subject to FIPPA.

The Ministry is requesting authorization for the public bodies to indirectly collect personal information from two new national donor registries developed by Canadian Blood Services -- the National Organ Waitlist ("NOW") and the Highly Sensitized Kidney Patients registry ("HSP"). In support of its request, the Ministry provided a privacy impact assessment prepared by the Canadian Blood Services for the National Organ Registry Management System dated June 17, 2011 and a privacy impact assessment for the data transfer between BC Transplant Society and Canadian Blood Services prepared by the Provincial Health Services Authority dated March 16, 2012.

Canadian Blood Services is a not-for-profit organization incorporated under the *Canada Corporations Act* and subject to the *Personal Information Protection Act*. Its corporate members are Ministers of Health of all provinces and territories except Quebec. Canadian Blood Services has a mandate to design a national system for organ and tissue donation and transplantation in Canada. The new national donor registries are part of this mandate. The registries will employ a web-based business application operated in Ottawa. The intention is that there will be access to the registries in every province except PEI. The registries are scheduled to "go live" on May 27, 2012.

Canadian Blood Services will collect the personal information of participants (donors and recipients) into the registries and will use and disclose it for the purposes of determining suitable matches for waitlisted organ transplant recipients. This personal information will include demographic information (name, date of birth, gender, ethnicity, national and local donor ID), health information (blood group, height, weight), cause of death and time of death, results of serology tests and donor organ risk factors.

The National Organ Waitlist will provide a list of patients in Canada that are waiting for heart, lung, liver, pancreas, small bowel, and multi-organ transplants. It will facilitate organ donation and transplantation by providing real-time access to up-to-date information of both organ recipients and deceased organ donors. It replaces the national waitlist that the London (Ontario) Health Services Centre currently maintains.

The Highly Sensitized Kidney Patients registry will provide a list of those kidney patients who have such high levels of antibodies that there is only a limited chance of finding a donor match for them. It will increase transplant opportunities for these patients who are currently disadvantaged in terms of access to compatible donors.

The BC Transplant Society delivers or contracts for all organ transplant services in British Columbia. It contracts with Vancouver General Hospital, St Paul's Hospital and BC Children's Hospital for inpatient and outpatient transplant services. It also funds local transplant clinics in all Health Authorities.

The BC Renal Agency's clinical information system ("PROMIS") will interface directly with the registries. All of the clinics use the PROMIS database to input information and manage patient care. The PROMIS database makes it possible to have all of the transplant relevant data available to physicians providing care to the patients. The exchange of information will occur between the PROMIS database and the national

donor registries situated on servers located in Ontario. The information from the national donor registries will be viewed by Health Authorities through the PROMIS database.

## **DISCUSSION**

The question that I must decide is whether to authorize the public bodies to collect the personal information of donors and recipients from NOW and HSP.

### **■ Ministry of Health's submission**

The Ministry submits that the public bodies have the authority to collect the personal information of out-of-province recipients and donors from the registries under s. 26(c) of FIPPA because the information relates directly to and is necessary for a program and activity of the public bodies (programs that provide for organ and tissue donation and transplantation). The Ministry submits that it is not practical to collect the personal information directly from the individual in all cases. It cites the following as examples of cases where direct collection is impractical:

- recipients of organ and tissue donation and transplantation may be comatose or otherwise unable to provide consent,
- donors may be deceased or comatose and may have substitute decision-makers acting on their behalf, and
- individuals residing outside of British Columbia are not patients of the public bodies.

The Ministry further submits that there may be authority for the indirect collection of personal information from BC residents as a result of the combined effect of the *Human Tissue Gift Act*, its Regulations and s. 27(1)(a)(iii) of FIPPA. However, the Ministry questions whether the public bodies have the authority to collect personal information about donors and recipients located in other provinces. Therefore, it requests authorization of indirect collection under s. 42(1)(i) of FIPPA for the indirect collection of the personal information of donors and recipients located in other provinces. The Ministry indicated that designation of the PROMIS database as a health information bank under the *E-Health (Personal Health Information Access and Protection of Privacy) Act* would be impracticable and inappropriate from an operational perspective.

## ■ Reasons for granting authorization

The information collected by Canadian Blood Services and contained in the national donor registries is “personal information” within the definition of FIPPA. Moreover, it is highly sensitive personal information because it includes details about individuals’ health status.

Section 27(1)(a)(iii) of FIPPA permits another method of collection where it is authorized by an enactment. The Ministry submits that the *Human Tissue Gift Act*, the Consent to Donation Regulation and s. 27(1)(a)(iii) of FIPPA authorize indirect collection of the personal information of BC residents from the national donor registries by public bodies. The *Human Tissue Gift Act* provides for the consent by an individual, or an individual’s next of kin, to the use of the individual’s organs for donation. The Consent to Donation Regulation made pursuant to that Act requires certain health care facilities within BC to notify the BC Transplant Society of a death or an impending death of any patient younger than 76 years of age. Notification includes disclosure of personal information including any past and current medical history which is relevant to organ transplantation. To that extent, these provisions, together with s. 27(1)(a)(iii) of FIPPA, authorize the indirect collection of the personal information of donors by the BC Transplant Society from certain health care facilities in BC.

It must be considered whether this specific authority extends to a data flow through the NOW and HSP databases. Canadian Blood Services will use and disclose that personal information to BC Transplant Society as well as to other health care facilities in Canada. Clearly, the *Human Tissue Gift Act* did not contemplate data flows of this nature through electronic databases of another organization subject to the *Personal Information Protection Act*. However, given that it is the same personal information that is being recollected, I concur with the Ministry’s position that the indirect collection of the personal information of BC residents from NOW and HSP is authorized under the *Human Tissue Gift Act*, the Consent to Donation Regulation and s. 27(1)(a)(iii) of FIPPA.

With respect to the indirect collection of the personal information of donors and recipients located in other provinces from NOW and HSP, this can only be authorized by the exercise of my discretion to authorize it under s. 42(1)(i).

In a previous decision where the exercise of the Commissioner’s discretion under s. 42(1)(i) was at issue<sup>1</sup>, former Commissioner David Loukidelis considered the following questions in assessing the application:

1. Has a clear and sufficiently compelling public interest or objective been identified that cannot reasonably be accomplished through direct collection of personal information?

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<sup>1</sup> Auth (s. 42) 01-01, April 19, 2001.

2. Is the requested departure from FIPPA's rule of direct collection clearly justified when judged against the nature of the personal information to be collected and the purpose for which (and to whom) it is to be disclosed or used?

I have chosen to consider these same questions in this application.

With respect to the first question, I find that improving the availability of organs for transplant purposes in order to save lives is a clear and sufficiently compelling public interest or objective. I accept the Ministry's submission that it is not practicable for the public bodies to collect the personal information required for this purpose directly from the individual the information is about.

With respect to the second question, I find that although the personal information to be collected by public bodies is highly sensitive, the collection of that personal information for the purpose of saving lives with organ transplantation is appropriate and the departure from FIPPA's rule of direct collection is clearly justified.

## **AUTHORIZATION**

For the reasons noted above, under s. 42(1)(i) of FIPPA, I authorize the public bodies to indirectly collect personal information relating to donors and recipients located outside of British Columbia from the NOW and HSP national donor registries operated by Canadian Blood Services.

March 30, 2012



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Elizabeth Denham  
Information and Privacy Commissioner  
for British Columbia

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