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Information and Privacy Commissioner/Ontario

# Status Report

## Section 39(1)(c) Registries under the *Personal Health Information Protection Act*

### Overview of Section 39(1)(c) of the *Personal Health Information Protection Act*

Section 39(1)(c) of the *Personal Health Information Protection Act* (the *Act*) permits a health information custodian to disclose personal health information about an individual, without consent, to a prescribed registry of personal health information for purposes of facilitating or improving the provision of health care or that relates to the storage or donation of body parts or bodily substances.

Registries that have been prescribed in Regulation 329/04 of the *Act* are the Cardiac Care Network of Ontario in respect of its registry of cardiac services, INSCYTE Corporation in respect of CytoBase, London Health Sciences Centre in respect of the Ontario Joint Replacement Registry and the Cardiac Stroke Network in respect of the Canadian Stroke Registry.

### Mandate of the Information and Privacy Commissioner/Ontario

Section 13(2) of Regulation 329/04 of the *Act* requires prescribed registries to implement practices and procedures to protect the privacy of individuals whose personal health information is received, and to maintain the confidentiality of that information.

Regulation 329/04 of the *Act* further requires that the practices and procedures be approved by the Information and Privacy Commissioner/Ontario prior to November 1, 2005.

### Procedure for the Review of Practices and Procedures of Prescribed Registries

The following is the procedure that the Information and Privacy Commissioner/Ontario will follow in the review and prior to any approval of the practices and procedures of prescribed registries.

Prescribed registries are required to file copies of all privacy policies, procedures and brochures and copies of all human resources and security policies, procedures and agreements that relate to the protection of privacy of individuals whose personal health information is received, and that relate to maintaining the confidentiality of that information, including:

- confidentiality, data sharing, research and other third party agreements;
- policies on the provision of staff privacy and security training and education;
- policies and procedures on retention and disposal of personal health information;



- policies and procedures on de-identification and linking personal health information;
- security audits, disaster recovery plans and privacy crisis management protocols;
- privacy impact assessments and privacy audits;
- administrative, technical and physical safeguards implemented to safeguard security;
- documents outlining data holdings, the roles and responsibilities in relation to privacy and security and the contact persons appointed for privacy and security; and
- protocols for reviewing external requests for personal health information.

Within one month of receipt, the Office of the Information and Privacy Commissioner/Ontario will review the documentation and will conduct a site visit of the prescribed registry.

### Status of the Review of Practices and Procedures of Prescribed Registries

A preliminary meeting was held in March 2005 with representatives of each of the prescribed registries to outline the expectations of the Information and Privacy Commissioner/Ontario in relation to transparency and accountability, and to outline the procedure that will be followed in the review and prior to any approval of the practices and procedures of the prescribed registries.

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