

Statement of Information Practices at the Ontario Tumour Bank

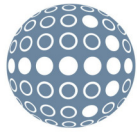
What is the Ontario Tumour Bank?

The Ontario Tumour Bank (OTB) is a provincial resource that collects tissue, blood and personal health information (PHI) from volunteer participants to use for research purposes. OTB is one of several programs managed by the Ontario Institute for Cancer Research (OICR), a not-for-profit corporation that is funded by the Government of Ontario through the Ministry of Research and Innovation.

Tissue, blood, and associated PHI is collected from volunteer participants who provide written consent at one of five (5) collection centres in Ontario: Credit Valley Hospital (Mississauga), Kingston General Hospital (Kingston), London Health Sciences Centre (London), St. Joseph's Healthcare Hamilton (Hamilton) and The Ottawa Hospital (Ottawa). Researchers may request samples and data from OTB by submitting an application form and a Material Transfer Agreement. The Ontario Cancer Research Ethics Board (OCREB) reviews all requests to determine that researchers are accredited, their projects have the potential to benefit cancer patients and that they have the necessary measures in place to protect the privacy of participants and confidentiality of the samples and data. Once OCREB approval is granted, samples and data are provided to researchers.

Where does OTB get PHI?

OTB collects its information via patient consent at its hospital collection centres, classified under the *Personal Health Information Protection Act, 2004* (PHIPA) as 'health information custodians' (HICs). OTB's central database is linked to additional information from Cancer Care Ontario (CCO). CCO is designated as a 'prescribed entity' under PHIPA.



What types of PHI does the OTB collect?

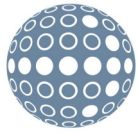
OTB collects tissue and blood samples as well as PHI from patient charts. The samples and de-identified data are utilized to assist researchers in the understanding, diagnosis and treatment of cancer. PHI from the patient chart includes diagnosis, age at time of collection, gender, histopathology (e.g., size of tumour, extent of disease), staging, patient history (e.g., weight loss, history of smoking, pregnancies), family history (e.g., family history of cancer, cancer type, age at diagnosis), outcome (e.g., local recurrence, distant progression), systemic therapy (e.g., start/end dates, cycles, agents), radiotherapy/brachytherapy (e.g., start/end dates, doses), comprehensive surgical data (e.g., relevant types and dates of procedures) and toxicities (e.g., date, grade, status). PHI from CCO's Ontario Cancer Registry includes additional outcome, diagnosis and treatment details.

Currently all PHI held by OTB is collected, used and disclosed by the hospital collection centres (HICs under PHIPA) pursuant to written consent and by CCO according to its mandate as a prescribed entity under PHIPA.

How does the OTB use PHI?

OTB uses the information it collects to disseminate tissue samples and de-identified health information to researchers who have had their studies approved by OCREB.

The information held by OTB is only used to facilitate and improve the provision of health care for cancer patients through an increased understanding of the disease. OTB provides samples and data to facilitate the understanding, diagnosis and treatment of cancer, which will ultimately enhance patient care. Researchers are only provided with de-identified data.



To whom does OTB disclose PHI?

OTB may disclose de-identified PHI to researchers whose research proposal is approved by OCREB. OTB discloses PHI to CCO, for the purpose of linking the information collected at the HICs to information from CCO.

How can I get access to my information?

Persons requesting access to their PHI will be directed to the health information custodian where the original information was collected.

Whom can I speak to if I have questions about OTB's information practices and privacy program?

Questions or concerns related to OTB's information practices or privacy program should be directed to:

Ontario Tumour Bank
Project Director
Ontario Institute for Cancer Research
MaRS Centre, South Tower
101 College Street, Suite 800
Toronto ON M5G 0A3
Telephone: 416-673-6639

Questions or concerns may also be directed to
Ontario Information and Privacy Commissioner
Office of the Information and Privacy Commissioner/Ontario
2 Bloor Street East, Suite 1400
Toronto ON M4W 1A8
Telephone: 416-326-3333 or 1-800-387-0073
TDD/TTY: 416-325-7539
<http://www.ipc.on.ca/>