

Patient Partnership Initiative Privacy Policy

This Privacy Policy sets out the collection, use and disclosure of personal information associated with your voluntary participation in the Patient Partnership Initiative (the “Initiative”) of the Ontario Institute for Cancer Research (“OICR”, “we”, “our”). The purpose of this Initiative is to integrate patient perspectives and insight across OICR’s priorities, programs and processes.

To carry out the Initiative, we have formed an OICR Patient Community, a group composed of patients, caregivers or other family members that have voluntarily consented to register and participate in the Initiative (“Patient Community Members”). Patient Community Members often take on roles within OICR projects and OICR-supported projects. For example, some of our Patient Community Members may be asked to participate in the OICR Patient and Family Advisory Council (“PFAC”), which will advise OICR on all matters relating to the Initiative.

How We Collect and Use Your Personal Information

If you choose to participate in the Initiative, and register to become a Patient Community Member, we will collect and use the types of personal information identified below as follows:

1. **Contact information**, such as name, email and phone number will be collected if you choose to register to participate in the Initiative. This personal information will be used to contact and communicate with you for Initiative purposes including:
 - a. reviewing applications for research funding,
 - b. helping researchers ensure their work benefits patients,
 - c. working with us on communications related to the Initiative or OICR, or
 - d. facilitating your participation in voluntary cancer research projects.
2. **Survey information**, namely, your responses to survey questions will be collected if you choose to participate in a survey which we may circulate from time to time. Participation in any survey is completely voluntary, and we will use this information in order to improve our patient partnership practices, for accountability reporting purposes, and to facilitate patient partnership in cancer research.

With whom We may share Your Personal Information

Your personal information will only be shared with OICR staff and/or OICR-supported researchers who have a need to know such information to carry out the Initiative’s purposes set out above and who are bound to keep this information confidential.

Please note that in limited circumstances, we may disclose your personal information to third parties if we believe the disclosure is necessary to meet any legal requirement or enforceable governmental request or if an emergency threatens the life, health or security of an individual.

How We Safeguard your Personal Information

Your personal information will be maintained in an encrypted and password-protected format on OICR servers. All such information will be retained only for so long as is necessary to achieve the purposes set out earlier in this policy or until you withdraw your consent to the use of your personal information, which you may do at any time by emailing us at: patientpartnershipteam@oicr.on.ca.

Privacy Policy Changes

We may update or otherwise modify this privacy policy periodically. We shall notify you of changes to this privacy policy by posting the revised policy on the Initiative website.

Questions or Concerns?

If you would like to learn more about our commitment to protecting privacy, please see the OICR [organizational Privacy Policy](#). You may also view our [Information Practices Frequently Asked Questions](#).

If you have any question or concerns, please contact us at:
patientpartnershipteam@oicr.on.ca.