

Frequently Asked Questions Participation Policy and Client Registry

Q. What is the Research Participation Policy about?

A. The Baycrest Research Participation Policy (X-80) states that all clients may be approached by research staff to be invited to participate in research studies. The policy was developed to ensure that all clients have the opportunity to participate in research that they are eligible for.

Q. Why did Baycrest introduce this policy?

A. Integrating care, research and education is a main strategic area of focus for Baycrest Health Sciences. The participation policy aligns with this strategic goal of becoming the leading academic health sciences centre focused on transforming the aging experience. The integration of research, education and clinical care is key to developing the best treatments and services for clients.

Q. What is the Baycrest Client Registry?

A. The Baycrest Client Registry is a confidential database that contains a limited selection of health information.

Q. How do I become enrolled in the Baycrest Client Registry?

A. All current Baycrest clients, inpatients and outpatients (who do not choose to opt out before **April 1, 2014**) are automatically enrolled in the Baycrest Client Registry.

Q. What information is kept in the Registry?

A. The Registry contains the following information:

- facility location of client (Apotex Centre, hospital unit, Terraces, outpatient)
- gender
- age
- diagnosis
- MDS Memory assessment
- current medications (category only)
- use of assistive devices, such as glasses, hearing aid, walker
- language preference and abilities

The health information is anonymous; it **does not** contain any personal identifiers such as name, ID number or health card number.

Q. How does research use the information in the Client Registry?

The Client Registry will help researchers identify clients who may be eligible for specific research studies going on at Baycrest. The Client Registry allows researchers to search for clients who qualify or meet the exact requirements of their specific study. Researchers cannot browse through the health information.

Q. Who has access to the information in the Client Registry?

A. Only Baycrest researchers conducting studies that have been approved by the Baycrest Research Ethics Board will have access to the Client Registry.

Q. Does being in the Client Registry mean I *must* participate in research?

A. **No.** Being in the Client Registry simply means that you *may* be approached by a researcher and invited to participate in a study.

Frequently Asked Questions Participation Policy and Client Registry

Q. Do I have a choice?

A. Yes. You may choose to participate or decline participation **at any time**, even after a study is underway.

Q. What will a researcher do if my name comes up in the Client Registry?

A. If your information matches a specific study you will be contacted by a researcher and asked if you are interested in hearing more about the study. The researcher will give you details about the study so you are able to decide whether or not you would like to participate in it.

Q. If I don't want my information in the Baycrest Client Registry, how can I get out of it?

A. There are many ways to opt out of the Registry. You can:

- tell a member of your care team
- tell the researcher when he or she comes to visit
- call the **Research Hotline** at 416-785-2500 ext. 2900 or
- send an email to ResearchHotline@baycrest.org and ask to be removed.

Q. Is there a time limit to opt out or get back in?

A. No. There is no time limit. You can opt out of the Client Registry, or opt back in, at any time.

Q. Who do I call if I have questions?

A. For more information about the policy, the Client Registry or a study, please call the **Research Hotline** at 416.785.2500 ext. 2900 OR send an email to ResearchHotline@baycrest.org.

Q. Where can I find more information?

A. Information, including an FAQ and downloadable brochure are available on the Baycrest website at www.baycrest.org/clientregistry.

Brochures are also available at all nursing stations throughout the Apotex Centre, hospital, outpatient clinics and The Terraces of Baycrest.

Q. What do I do if I have a comment or a complaint?

A. We welcome your comments and appreciate the opportunity to respond to a complaint. Please call the **Research Hotline** at 416-785-2500 ext. 2900 or send a detailed email to ResearchHotline@baycrest.org. Alternatively, you can contact the Baycrest Privacy Officer at 416-785-2500 ext. 3443 or Baycrest's Ombudsperson at ext. 2919.