

Frequently Asked Questions Participation Policy and Client Registry

Q. Why did Baycrest introduce a Research Participation Policy ("Policy")?

A. Integrating care, research and education is a main strategic area of focus for Baycrest. The 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 Research Participation Policy about?

A. The Baycrest Research Participation Policy (X-80) states that based on their implied consent, all clients may be invited to learn about participating in specific research studies. The policy was developed to ensure that all clients have the opportunity to participate in research for which they are eligible.

Q. What is the Baycrest Client Registry ("Registry") and what information does it hold?

A. The Registry is a secure database that 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 data in the Registry does not contain any names, ID numbers or health card numbers.

Q. How do I become enrolled in the Registry?

A. All current Baycrest clients, inpatients and outpatients are enrolled in the Registry, based on their implied consent and an active notice campaign where Baycrest keeps you up to date on the Registry and research activities at Baycrest. You can choose to withdraw that consent by contacting the **Research Hotline** at 416-785-2500 **ext. 2900** or send a detailed email to **ResearchHotline@baycrest.org**.

Q. How is the information in the Registry used?

A. The Registry will help researchers identify clients who may be eligible for specific approved research studies at Baycrest. It allows researchers to search for individuals who qualify or meet the exact requirements of their specific study.

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

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

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

A. No. Being in the Registry simply means that you may be approached by a researcher and invited to participate in a study. It is essentially a 'permission to contact' model, and you can decline to learn more about a given study, or even once you learn about it, can decline to participate in it.

Q. Do I have a choice about whether to participate in a study that I am approached about?

A. Yes.

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

A. If your information makes you eligible for a specific study, you will be contacted by Baycrest and asked if you are interested in hearing more about the study. If you are interested, a researcher will give you details about the study so that 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 Registry, how can I withdraw?

A. 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; if you choose this method, you are acknowledging that email is not 100% secure, but want to use it anyway.

Q. Is there a time limit to ask that information not be stored in the Registry, or if I change my mind, to have it put back in?

A. No. There is no time limit. You can ask not to be included in the Registry, or have your information removed, at any time.

Q. Whom do I call if I have questions?

A. For more information about the policy, the Registry or a specific study you have heard about, 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, Baycrest 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**.
