

connect2research

Question & Answer about Holland Bloorview's research notification program

connect2research is a secure database that connects to limited information such as date of birth, diagnosis, and contact information in a Holland Bloorview client's electronic health record.

The database will help identify and directly connect Holland Bloorview researchers with clients and families (past or present) who may be eligible for a research study.

A client's health record is protected information and at no time will it be visible to anyone besides your authorized care team.

All current clients of Holland Bloorview are automatically included in connect2research unless they choose to withdraw. Clients and families can withdraw from the connect2research database at any time by calling us at (416) 425-6220 ext. 3000 or emailing

connect2research@hollandbloorview.ca. Your decision, to be included/not included in the connect2research database or to participate in a research study, will not affect the care or services you receive at Holland Bloorview.

Holland Bloorview is committed to protecting your privacy and keeping your information secure. In compliance with the Personal Health Information Protection Act (PHIPA), all healthcare information is kept strictly confidential, secure and protected. For any questions regarding privacy, please contact the Privacy Office at (416) 425-6220 ext. 3467 or email privacy@hollandbloorview.ca.

Questions:

1. What is research and what are the benefits of participating in research
2. What is connect2research and how is this different from connect2care
3. Why "connect2research"
4. Does connect2research impact my care at Holland Bloorview
5. Do clients sign-up for connect2research, or are clients automatically included
6. How do I withdraw from connect2research
7. What happens when I withdraw from connect2research
8. Who is included in the connect2research database
9. How do we ensure your privacy
10. How does the connect2research database work
11. What information is the connect2research database accessing
12. Who can access information in connect2research
13. What information will research teams see
14. How often can I expect to hear from a research team
15. Is connect2research a research study
16. Do I have to participate in research
17. Where can I find more information or provide comments about connect2research

Q. What is research and what are the benefits of participating in research?

A: Research can help us learn more about disabilities, technologies and treatments and help build the most meaningful and healthy futures for all children, youth and families. Holland Bloorview is dedicated to improving the lives of children with disabilities through client and family-centred rehabilitation research. Our research has led to advancements in interventions and improved outcomes for children and youth with disabilities and their families.

Every research study is different – while some involve surveys, interviews, and assessments - others may include physical activity, investigational medications and technology. It is entirely up to a client and their family to decide what research study is right for them. You may or may not receive direct benefits from participating in a research study. For example, some studies might offer parking or a small token of appreciation such as a gift card for participating, while other studies might not.

Q. What is connect2research and how is this different from connect2care?

A: connect2care and connect2research are unique to Holland Bloorview:

- **connect2care** is an online tool that gives clients and families of Holland Bloorview complete access to their health care information, health records, appointments, and notes from clinical visits 24 hours a day, seven days a week. [Learn more](#)
- **connect2research** is a secure database that directly connects Holland Bloorview researchers with clients (past or present) who may be eligible for a research study. The database connects to limited information such as date of birth, diagnosis, and contact information in a Holland Bloorview client's electronic health record. Clients can choose to participate or decline on a study-by-study basis. [Learn more](#)

Q. Why “connect2research”?

A: connect2research will help increase awareness of new research occurring at Holland Bloorview and provide equal access for all clients and families who may be interested in learning more or participating. connect2research will provide more clients and families the opportunity to be aware of, and participate in, innovative research taking place at Holland Bloorview.

Q: Does connect2research impact my care at Holland Bloorview?

A: No. Your decision to be included/not included in the connect2research database or to participate/not participate in a research study will not affect the care or services you receive at Holland Bloorview.

Q. Do clients sign up for connect2research, or are clients automatically included?

A: All clients aged 21 and under that has received services at Holland Bloorview after May 1, 2011, or are aged 22 to 28 who have received services at Holland Bloorview in the last two years are automatically included in connect2research unless they choose to withdraw. The connect2research office may contact you to collect additional optional information such as email address and access technologies used, with your permission.

Q. How do I withdraw from connect2research?

A: You can choose to withdraw at any time. To withdraw, please contact the connect2research office at (416) 425-6220 ext. 3000 or email connect2research@hollandbloorview.ca. You can also tell a member of your health care team or a researcher that you wish to withdraw and they will inform the connect2research office on your behalf.

Q. What happens when I withdraw from connect2research?

A: When you withdraw from connect2research, we will remove you from the connect2research database. You will not be included in any new recruitment notification lists after this time and you will not be contacted by researchers about any new research studies you may be eligible for in the future.

You can enrol into connect2research at any time or visit [Participate in Research](#) to learn about research opportunities at Holland Bloorview.

If your name and contact information was provided to a Holland Bloorview researcher before you withdrew, you may still receive a call or information in the mail about a research project.

Q. Who is included in the connect2research database?

A: In Phase One of our connect2research roll-out, only clients aged 21 and under who have received services at Holland Bloorview after May 1, 2011, or are aged 22 to 28 who have received services at Holland Bloorview in the last two years and have not withdrawn from connect2research will be included in the connect2research database.

Q. How do we ensure your privacy?

A: Holland Bloorview's connect2research database fully complies with and follows the *Personal Health Information Protection Act, 2004* ("PHIPA") in the use of limited personal health information for research participant recruitment purposes. A client's health record is protected information and at no time will it be visible to anyone besides your authorized care team.

Q. How does the connect2research database work?

A: The connect2research database uses a secure hospital-approved software program that connects to limited information in a Holland Bloorview client's electronic health record and only allows the connect2research office to enter search terms of a specific study into the database. The database will generate a list of clients who match the specific study terms. Holland Bloorview researchers will only receive name and contact information for clients who match the specific search terms.

A Holland Bloorview researcher may call or send you information in the mail to ask if you are interested in learning more about a research study or project, and you can choose to participate or decline on a study-by-study basis.

Q: What information is the connect2research database accessing?

A: The following details are search criteria in the connect2research database that help identify clients who may be eligible to participate in a specific research study:

- Chart number
- First and last name
- Date of birth
- Biological sex
- Home address
- Primary contact
- Phone number
- Reason for referral
- Diagnosis
- Date of diagnosis
- Gross Motor Function Classification System (GMFCS) level
- What clinics/programs client has accessed
- Languages spoken
- Interpreter required (y/n)

Q. Who can access information in connect2research?

A: Only the connect2research office and Holland Bloorview research teams working on studies approved by the Research Ethics Board (REB) will have access to connect2research on a study-by-study basis. Everyone using connect2research must complete training and follow institutional policies related to accessing, receiving, storing and destroying information to protect client privacy and personal health information.

A: What information will research teams see?

A: Holland Bloorview researchers will only receive names and contact information for clients who match specific search terms for a research study. No personal health information is shared between the connect2research database and any individual at Holland Bloorview.

Q. How often can I expect to hear from a research team?

A: How often you are contacted by a research team will depend on the eligibility criteria of studies at Holland Bloorview. You may be contacted a few times in a month or no times in a month. connect2research gives access to approximately 16,000 clients to learn about and participate in research at Holland Bloorview.

The connect2research office does not limit how many times a client and family can be contacted by different research studies as we believe clients and families should have the choice about what studies they would like to hear about and participate in. If you feel that you are being contacted too often, please contact the connect2research office.

Q: Is connect2research a research study?

A: No, connect2research is not a research study. It is a research notification database to communicate new research opportunities to eligible clients and families (past or present).

Q: Do I have to participate in research?

A: No. You do not have to participate in any research study if you choose not to. Your decision to participate in a research study, or to be included/not included in the connect2research database, will not affect the care or services you receive at Holland Bloorview.

Q. Where can I find more information or provide comments about connect2research?

A: If you have any questions or concerns about connect2research, you may do the following:

1. Visit our website at hollandbloorview.ca/connect2research
2. Contact the connect2research office at (416) 425-6220 ext. 3000 or email connect2research@hollandbloorview.ca
3. Depending on the nature of your comment, you may also want to contact Holland Bloorview's Privacy Office at (416) 425-6220 ext. 3467 or email privacy@hollandbloorview.ca