Data sharing through local, national, and international research partnerships and data consortiums at Holland Bloorview

Frequently Asked Questions

As Canada's largest pediatric rehabilitation hospital fully affiliated with the University of Toronto, Holland Bloorview Kids Rehabilitation Hospital is transforming care to enable the most meaningful and healthy futures for children, youth and families like yourselves.

We are committed to informing and developing new pediatric innovations and more personalized treatments to meet the unique physical, mental, and developmental needs of clients and families. We are also committed to better understanding and addressing the unmet needs of underserved populations.

Accessing and harnessing the power of clinical, administrative and demographic data is essential to these commitments.

By using and sharing de-identified clinical, administrative and demographic data from specialized children's hospitals across the province, country and globe, we can speed up the development of personalized therapies and interventions as well as improve and predict outcomes for children and youth with disabilities, developmental differences, and rare genetic conditions.

Over the next several years, Holland Bloorview will be partnering locally, nationally, and internationally with research partners and data consortiums to bring the health data of children with disabilities and developmental differences together. These partnerships will close the innovation gap and revolutionize pediatric disability and developmental differences care and services at Holland Bloorview and across the world.

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1. Who owns the data in an electronic medical record (EMR)?

Clients are the owners of their personal health data and Holland Bloorview is the custodian of that data. Consent to collect and store personal health data within the EMR is provided when a child or youth becomes a client at Holland Bloorview.

2. Where is personal health data stored? Who is it shared with and why?

Client data is stored in the secure electronic medical record (EMR) Holland Bloorview uses called Meditech.

We collect and use health information in Meditech to provide the best care possible.

To ensure the best in client and family-centred care, Holland Bloorview may share personal, identifiable health information with other health-care institutions, health regulatory agencies, agencies and businesses directly related to a client's care and research teams at Holland Bloorview. This data is shared to coordinate care, improve quality of services and to comply with government regulations.

3. **What laws and regulations protect personal health data?**

There are two important laws in Canada which protect data and, specifically health information.

- PHIPA – Personal Health Information Protection Act (Link here)
- PIPEDA – Personal Information Protection and Electronic Documents Act (Link here)

4. **What is de-identified data?**

De-identified data is any data from the electric medical record that does not include direct client identifiers such as their name, health card number or address, etc.

5. **Can you give examples of what types of de-identified data are shared?**

Examples of de-identified data shared include:

- Diagnosis – for example autism or cerebral palsy
- Height and weight
- Age
- Medications
- Treatments or services accessed
- Length of stay (inpatient clients)
- Language, race, ethnicity, sex

6. **Does Holland Bloorview share de-identified client data with local, national, and international research partners and data consortiums?**

Yes. By using and sharing de-identified client data with research partners and data consortiums, we can accelerate the development of personalized therapies and interventions as well as improve and predict outcomes for children and youth with disabilities, developmental differences and rare genetic conditions.

Research partnerships and data consortiums will close the innovation gap and revolutionize pediatric disability and developmental differences care and services at Holland Bloorview and across the world.

7. **Can you give some examples of what researchers or pharmaceutical partners might be looking at?**

A researcher who is studying how to predict and tailor the most optimal medication treatments for neurodiverse children may pull de-identified clinical data on diagnosis, age and drugs accessed. A pharmaceutical partner who is developing a new drug for spinal muscular atrophy may pull de-identified clinical data on diagnosis, treatments accessed and age.

8. **What is my/my child’s de-identified client data being used for through these research partnerships and data consortiums?**

De-identified client data from electronic medical records (EMR) is used to gain insights into client outcomes such as personalized treatment plans for those with rare disease. It is also used to develop more tailored products, medical treatments, devices or new drugs for children and youth with disabilities and developmental differences.

9. **Will Holland Bloorview also be sharing client data with other health-care institutions or primary care providers to streamline my care?**

This initiative is focused on data sharing to advance discoveries and innovations in the field of pediatric disability. However, Holland Bloorview is committed to streamlining and supporting transitions to other care providers across the health care system. We share medical records with external care providers, with client/family consent, and we will continue to support and comply with large provincial initiatives such as Connecting Ontario to advance the access of digital medical records across the health care system.

10. How does sharing my data with research partnerships and data consortiums benefit me as a client/my child, youth, and/or family?

There is no immediate or direct benefit to children, youth, and families. However, there are many indirect benefits.

By sharing de-identified clinical data, commercial innovators and researchers can accelerate the discovery of solutions for complex medical conditions or treatments tailored to the unique needs of clients with disabilities and developmental differences. This will lead to more personalized and timely interventions for children, youth and their families, now and well into the future.

It will also help health-care providers and policymakers design more targeted programs and services to address the unique needs of these children, improving overall health outcomes and support services.

11. Is the client data shared through these research partnerships and data consortiums identifiable?

No. The information that Holland Bloorview shares will be stripped of direct client identifiers. In other words, all client data shared will be de-identified.

12. What safeguards are being put in place if the data leaves Canada?

No directly identifiable information will leave Holland Bloorview’s data system. Privacy enhanced technology will be used to limit re-identification potential, and the data remains protected and used ethically.

13. How many years of client data is Holland Bloorview sharing through these research partnerships and data consortiums?

Beginning in the summer of 2025, Holland Bloorview will share five years of retroactive data for all active clients (clients who have had an appointment or received services within the last two years). For example, if a client started receiving services at Holland Bloorview on January 1, 2018 and is still an active client in 2025, de-identified data within the electronic medical record from the summer of 2020 onward may be shared.

14. Is the de-identified data of former clients of Holland Bloorview being shared through these research partnerships and data consortiums?

Only clients who have received services at Holland Bloorview in the last two years will have their data shared. Clients who have not received services at Holland Bloorview since summer 2023 will not have their data shared.

For example, if a client's last visit was January 1, 2022, no data would be shared. If a client’s last visit was September 10, 2023, the last five years of their health data within the electronic medical record could be shared.

15. Is the privacy of clients and families/legal guardians at Holland Bloorview being compromised by sharing data through these research partnerships and data consortiums?

No. Client confidentiality is Holland Bloorview's top priority.

All data being shared will be stripped of direct identifiers, which means it will not include any personal information such a client's name or health card number.

Specific and pre-identified and agreed-upon data will be pulled into a separate and secure database that will reside within Holland Bloorview.

16. How will Holland Bloorview prevent data breaches?

Before we agree to any data partnership or consortium that involves data sharing, Holland Bloorview will complete the due diligence required to ensure the appropriate and compliant safeguards and on-going monitoring tools are in place to protect your data from unauthorized use.

Holland Bloorview will store clients' de-identified, clinical data being shared with a data consortium or a research partner in a separate, secure data warehouse, on a separate and secure computer server housed at the hospital. Data consortiums and research partners will then use privacy-enhanced technology to further protect the data before it is used.

17. Do clients and families/legal guardians have to consent to have their data being shared through research partnerships and data consortiums?

Consent to share identifiable health data with other health professionals, health regulatory agencies, health-related agencies and research teams is obtained upon initial registration and should be an ongoing conversation with care providers.

In the case of research partnerships and data consortiums, Holland Bloorview will be sharing de-identified clinical data, and our privacy statement will be amended as Summer 2025, to include this information.

Given this is a change to our current data sharing policy and privacy statement, we will notify all active clients as of June 1 2025, and they will be given 30 days to opt out before any data is shared. After the 30-day period, if a client does not opt out, client data will be shared with Holland Bloorview approved data consortiums or partnerships. However, clients/caregivers can opt out any time after the 30-day period if they change their mind.

18. How will Holland Bloorview be sensitive to clients and families/legal guardians who are uncomfortable sharing information based on their own cultural beliefs, values and experiences, including those who have experienced direct/indirect intergenerational medical trauma due to their lived and living experiences?

We understand that the decision by clients and/or their families/legal guardians to share de-identified clinical data is deeply personal and may be shaped by their unique experiences, cultural beliefs and values. We remain committed to respecting and honouring all perspectives and decisions by clients and families/legal guardians.

19. I do not want my/my child's data to be shared through research partnerships and data consortiums. How do I opt out?

Clients/caregivers can opt out of sharing their data through these research partnerships and data consortiums by completing a request form found on www.hollandbloorview.ca/datasharing. Please note that it will take up to two weeks to process the request to opt out.

20. Can I submit this opt-out form online through Connect2Care instead? If not, why?
The form is not currently available on Connect2Care. However, the Holland Bloorview team is working to create a version of the form that will be available to be submitted online through Connect2Care.

21. How would the identity of young clients be verified who want to opt out?
The following forms of identification are accepted to verify a client or the identity of their substitute decision maker:

Photo identification:

- Ontario Health Insurance Plan (OHIP)
- Driver’s license
- Government employment card
- Age of majority card
- Canadian citizenship card
- Indian status card
- International student card
- Ontario photo card
- Permanent resident card
- Firearms acquisition certificate (FAC)
- Canadian National Institute for the Blind (CNIB)
- Student Card

Non-photo identification:

- Ontario Health Insurance Plan (OHIP)
- Birth certificate
- Hospital card
- Canadian blood donor card
- Immigration papers

22. Who can make the decision to opt out?
This is a decision for clients and their families/legal guardians to make together based on their unique needs.

23: What is the process for opting out if there is a difference of opinion between the client and their family/substitute decision maker (i.e.: if one wants to opt out, but the other wants to participate)
If the client is 16 years old or older and capable of making their own decisions, the substitute decision maker’s decision should be aligned with the client's wishes. It’s also important to note that the client can legally make their decisions at this age and they don’t need to tell their family/substitute decision maker.

If the client is not able to make their own decisions, then the substitute decision maker will make decisions in the client’s best interest.

23. What happens to a client’s data once they opt out?

Once you opt out of sharing your data, your request will be captured in your electronic medical record and from that point on, your data WILL NOT be shared through these research partnerships and data consortiums.

24. How long will it take to process the request to opt out?

From the time you opt out, in can take up to 30 days for your request to be completed.

25. What are the risks of opting out of data sharing with research partners and data consortiums?

Please be assured your decision not to share your data will not affect the care or services you receive at Holland Bloorview.

However, it is important to note, that for research partnerships and data consortiums to be truly effective and have impact on diverse children and family across the system, representation in the data is critical. Each of us is different. We can and do contribute important and unique information to data sets. Without representative data sets, there is a risk that the discoveries, interventions, drugs and devices informed by these data sets will not be relevant to all children, youth, and families.

26. Who do I contact if I or a parent/caregiver/legal guardian has questions/comments about Holland Bloorview’s data-sharing initiatives or opt-out process?

You can email hbconnect@hollandbloorview.ca and we will respond to your query within three business days.