

This letter contains an important update in how we share clinical data.

A teaching hospital fully affiliated
with the University of Toronto

You are receiving this letter because you are an active client at Holland Bloorview. If there has been a change in your status or you have received this letter in error, please contact Holland Bloorview's Health Information Management to update your or your child's health record at (416) 425-6220 x 3422.

This letter is also available in Arabic, Bengali, Traditional Chinese, Simplified Chinese, Dari, Farsi, French, Spanish, Tamil, Urdu and Vietnamese at www.hollandbloorview.ca/datasharing

June 9, 2025

Dear client and family,

As Canada's largest pediatric rehabilitation hospital, fully affiliated with the University of Toronto, Holland Bloorview Kids Rehabilitation Hospital is transforming care to support 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.

Accessing and harnessing the power of health data is essential to these commitments.

For far too long, pediatric health data, especially pediatric disability health data, have not been used to inform innovation and transformation, which has led to a major innovation gap in the pediatric system.

By using and sharing **de-identified** data (data that does not include a client's personal information like their name or address) from the electronic medical record (EMR) with research partners and data consortiums, we can speed up the development of personalized therapies and interventions. We can also improve and predict outcomes for children and youth with disabilities, developmental differences and rare genetic conditions.

For example, researchers at Holland Bloorview are using de-identified data from the EMR to predict and improve medication outcomes for children with neurodevelopmental differences. If they can predict what medications a child may respond to, we can find the right medication faster with fewer trials - potentially improving a child's quality of life and overall health outcomes.

Beginning July 15, 2025, 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. Our first partnership is with KidSights Data Consortium – to learn more about it go to www.hollandbloorview.ca/kidsights.

What do these partnerships and data consortiums mean for me and my family?

If you are an active client (receiving services/care within the past two years) at Holland Bloorview, we will share de-identified data from your electronic medical records with data consortiums. This means your child's de-identified clinical data could be accessed by commercial innovators like global pharmaceutical and medical device companies or by academic researchers (including Holland Bloorview researchers). Why? So they can accelerate the discovery of solutions for complex medical conditions, including new medical treatments and interventions, drugs, medical devices or products.

If you consent to this, there is no further action required.

Can I opt out of sharing de-identified data?

Yes. You can opt out of sharing your de-identified data with data consortiums and researchers by filling out the opt-out form found on www.hollandbloorview.ca/datasharing by July 1st, 2025. If you do not opt out by that time, your consent to share de-identified data will be implied. However, you can opt out any time after July 1st if you change your mind. Please note that once your opt-out form has been received and approved, it will take up to two weeks to process.

We understand that the decision to share your information are deeply personal and may be shaped by your unique experiences, cultural values and beliefs. We are committed to respecting and honouring your perspectives. Please be reassured your decision not to share your information will not affect the care or services you receive.

How will Holland Bloorview share my data with research partners and data consortiums?

Holland Bloorview will only share de-identified clinical data, including information like client demographics, diagnosis, height, weight, age, treatment, time-range and setting (in/outpatient). This means it will not include any personal information such as a client's name, address or health card number.

Holland Bloorview is committed to protecting your privacy and keeping your information secure. In compliance with the Personal Health Information Protection Act (PHIPA), all health-care 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.

If you'd like to learn more about our membership with data-sharing consortiums, please visit www.hollandbloorview.ca/datasharing. You can also scan this QR code to watch a video of clients sharing de-identified clinical data and how they can opt out.



We are excited to be transforming care and services through data insights that will accelerate discovery and close the innovation gap for children, youth and families with disabilities and developmental differences around the world.

Sincerely,

A handwritten signature in black ink, reading "Julia Hanigsberg".

Julia Hanigsberg
President and CEO