

## **Frequently asked questions (FAQ) from clients, families and research participants**

### **1. What is demographic data?**

Demographic data refers to information that is collected to better understand a given population. For example, age, race, and sex; employment status, education, and income.

### **2. Why is Holland Bloorview Kids Rehabilitation Hospital collecting client, family and research participant demographic data?**

Our goal is to ensure that every client and research participant has access to the highest quality of health care and research opportunities that we can provide.

The information you provide will:

1. tell us who we serve and who participates in research,
2. help us plan for services that will be the most helpful for you/your child, and
3. help us improve quality of care and provide access to research for all.

### **3. My child is only here for an appointment. How is this relevant to their care?**

It is important for us know who we serve. When we ask, we learn about our clients' needs and what types of supports or services might be helpful. By collecting this information from everyone who comes through our doors, we become better at planning for client-centered, equitable services.

### **4. Is it illegal to ask me these questions?**

No. The Ontario Human Rights Code encourages the collection of this kind of data when the purpose is to monitor discrimination and promote equity.

### **5. What are you going to do with this information?**

Your information will be used by Holland Bloorview so that we can better understand who our clients, families and research participants are, plan for services, and ensure we are providing the best care and research opportunities for all the children and youth we serve. For example:

1. This data will allow us to examine whether client health and research participation are affected by factors such as language, disability, gender, etc.
2. This information will be reviewed and used for program development and improvement.

Your answers will also help us personalize care to your child's needs and plan for future studies and interventions.

### **6. Who can see my information?**

Your information will be seen by your child's care team, research team (with approval from the research ethics board) and a small number of research operations staff. It will be treated with the same level of confidentiality as all the other health information you share.

In cases of organizational learning projects or reporting to Ontario Health, the data will only be available in aggregate form. This means that your answers will be grouped with other answers and there will be no way to identify you or your child (i.e. no name, address, insurance information, etc.).

### **7. Why are you asking me about my child's disability (or race, sexual orientation, etc.)?**

Our goal is to be able to understand our clients', families' and research participants' needs and to clearly identify who is being served and participating in research studies at our hospital. We also know that sometimes people experience discrimination in health care. We want to make sure that is not happening here and if it is, we want to correct that.

Your answers will help us provide more specific care that meets your child's needs and provide relevant research opportunities.

As children are growing and developing, parents and caregivers may not know the answers to all these questions yet. Please select "don't know" or "prefer not to answer" if that feels most appropriate for your child and their development.

### **8. Why are you asking me about my child's place of birth?**

We want to make sure that no matter where a child or family comes from, or what their immigration status is, they get the best care and research opportunities possible.

### **9. Why do you need to know how much money I earn? Do you report this to any agency?**

No, we don't give your information to anyone outside of your child's circle of care and research team unless required by law. For many clients and research participants, knowledge about income will help us inform you about services and research opportunities you and your child may be eligible for and provide support for your unique needs.

## **Holland Bloorview**

Kids Rehabilitation Hospital

Research suggests that income can influence access to care and supports. Collecting this information helps us identify and address any potential barriers so that all families have equitable opportunities to care, services and research opportunities

### **10. Do I have to participate?**

No. Participation is completely voluntary.

If you have any questions about why we collect this information and how we use it, please ask your care team, Holland Bloorview's director of quality, safety and performance or the director of research operations and business development, Bloorview Research Institute.

*Adapted from materials developed by Health Equity Office, Sinai Health System for the "Toronto Central LHIN Measuring Health Equity" project (torontohealthequity.ca).*