

Tips for Researchers: Encouraging Clients & Families to Engage in On-Site Research

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Sept. 21, 2020 – Clients engaging in research at the Bloorview Research Institute is essential to moving childhood disability research forward. There are several ways for clients to participate in research, including engaging in research visits onsite at Holland Bloorview. Dr. Teenu Sanjeevan, a research fellow with the hospital's Autism Research Centre, offers these tips to researchers when they are speaking to prospective research participants and their families:

1. **Communicate to potential participants and their families that Holland Bloorview is safe.** Tell them that the hospital has is taking many precautions to help ensure the safety of everyone at our hospital. Here are some of the ways:
 - a. Everyone is pre-screened and screened upon entry
 - b. Everyone who is able to wears a mask
 - c. Have plexi-glass barriers throughout the hospital - in our research labs, assessment rooms, main reception
 - d. High-touch surfaces are frequently disinfected with medical-grade wipes

Clients and families can learn more about the hospital's COVID-19 precautions and updates before arriving for their or their child's study visit:

<https://hollandbloorview.ca/covid-19>

2. **Review every step of the study.** Re-assure the prospective participant and their family caregiver/parent that you will go over every step of the study so that they know what to expect during the study and are comfortable. Tell them that they will never be asked to do something that they are not comfortable with during the entire process.
3. **Put yourself in their shoes.** Try to frame the study from the participant's perspective – explain how participating in the study might of value to them. For example, will it help increase the understanding of a prospective client's diagnosis. Remember, you are asking them to take time out of their busy schedules to come to the hospital. There also

needs to be an understanding with the participant that direct benefits from a research study are not very common; however, they are helping researchers to find ways to develop customized interventions in the future for others who have similar diagnoses.

4. **Use lay language.** If you use language that is easy to understand when explaining your study and how it will benefit the potential client, they are more likely to consider participating. Make sure your voice is friendly and conversational in tone.
5. **Make the study fun.** How can you make your study more engaging for a child? If you are able to, consider playing up these activities so the child/youth see this as a fun outing with their parents. This may not be possible with all studies of course.
6. **Incentivize.** A gift card can go a long way in encouraging a child and their family member/caregiver to participate in your study. The participant will most likely see it as a reward for doing something fun and educational too. If offering a gift card or another monetary incentive is not possible, try suggesting the client can use their participation as volunteer hours (if they are a high-school student). Remember that these incentives need to be part of the REB-approved protocols. If they are not, the research should submit their amendments to the Research Ethics Board.

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