October 3rd, 2014

Dear ___________,

Last (winter/spring) you participated in our study called "**Ethical and social implications of long term involvement of children with IBD in biomedical research.**" In this study, you were interviewed about your experiences participating in medical research at CHEO. We wanted to thank you once again for participating and giving of your time and energy. Some of you expressed interest in hearing about the results of the study, and as a result, we have prepared this document containing a brief summary of the major findings.

Summary of Results:

How do Kids and Teenagers Feel About Participating in Medical Research?

Most kids and teenagers that we interviewed seemed to have a positive experience with research. Some spoke about the fact that they always say 'yes' when asked to participate because of past experiences and also because they feel like they are active contributors to knowledge on their illness. Others spoke about particular studies they participated in, describing these as fun and interesting. For example, one participant described taking part in a study where she got to jump up and down on a mat: "umm it was pretty easy I guess because there wasn't really much that you had to do umm but it was kind of fun too to in to go jump on a plate or something um yeah it was kind of a good time just to see all the other things that they can do to help stop Crohn's." Other participants who were trying out the Remicade medicine mentioned liking research because they got to miss an entire day of school. For many of the participants, taking part in research was second nature to them; they often described it as being for a worthy cause and a good use of their time.

A few of the kids and teenagers that we spoke to mentioned that they did not like particular aspects of research. Some talked about how some studies that they had participated in turned out to be either uncomfortable or too lengthy. For example, one participant described research involving an endoscopy as being invasive. She described the process as: "intrusive, and it kind of like goes into your personal privacy, and now for like the little kids they don't really understand what that means and then for the older kids its really, really intrusive and you know, you don't really want like people to look, be looking inside you, as well as the treatment that comes before the endoscopy where you..."Other participants talked about not wanting to participate in studies that require too much of a time commitment as they already had lengthy waits to see the doctor.

What Reasons Do Kids and Teenagers Have for Deciding to Participate in Research?

We found that the kids and teenagers in this study had several reasons for agreeing to participate in biomedical research. In the interviews, many people talked about taking part in research in hopes of helping others and preventing other children and teenagers from experiencing what they went through. Others spoke about helping in terms of giving back to the research community and being an active contributor towards IBD research. For example, one participant said "Like all the struggles that you're going through you want to help them find and figure out the best ways to cope, ways to fix it, you know it something that like I don't know if everybody feels like this but I feel like I don't want to ignore it like I want to be able to help in any way that I can like it feels like you're kind of a part of the situation. And so I think personally that research is actually a really good thing like its helping the, like our knowledge about the disease progress and then also it's kind of like helping you feel like you're able to do something important and give back".

Other participants mentioned that they chose to take part in medical research because the study sounded interesting or the activities involved sounded fun. Some kids and teenagers said that they took part in research because they hoped that the research would be helpful to them at some point during their treatment. Also, kids and teenagers talked about participating in research because their parents said it was a good idea and so they went along with it. Finally, many kids and adolescents said that participating in research was just something they do as a normal part of their visit to CHEO. These participants talked about giving samples for both treatment and research purposes during regular CHEO visits. For example one participant described how the difference in samples was explained to her: "usually when I'm talking with them when I have a meeting with Doctor X he tells me, you're gonna get this blood work for me so I can see how you're doing and you're gonna take this blood work for this research/person and this for this person or research". The participants described giving samples for research as a part of their normal care activity at CHEO.

What Reasons Do Kids and Teenagers Have for Deciding Not to Participate in Research?

We also asked participants about their reasons for not wanting to participate in research. One of the most common reasons expressed was that it would take up too much time. Many kids and their parents mentioned taking time off both school and work to be present at their CHEO appointments. As a result, asking for additional time for research purposes was described as an 'extra commitment'. Based on the interviews, another common reason for not wanting to participate in medical research was that the study involved an activity that the kids and teenagers were not comfortable with. A few kids in particular mentioned that they didn't like giving stool samples, so they would say no to any study which required them to give extra samples of their stool. Other kids said that they were uncomfortable being video recorded and would immediately say no to any study where they would have to be videotaped. For example, one participant explained that: "like the other day, maybe a month ago or two we were at CHEO and we were just going for a check-up and we got an invitation for a, X and I for a video interview and I didn't really want to but we ended up not doing it but I didn't really want to do it because I was just shy about it and stuff so I didn't really feel comfortable doing it but ya."

Conclusions

Overall, we conducted interviews with 25 children and adolescents with IBD (including a few parents). Based on these interviews, we found out important information about what kids and teenagers like and dislike about participating in research, why and how they choose to participate, and the experiences and challenges of living with IBD. These results show us that kids and teenagers with IBD have many different experiences with research. Overall, we found that the participants we interviewed usually thought about whether the study would be helpful (to themselves and others), whether it would be painful or uncomfortable, whether they had enough time, and what type of procedure was involved before agreeing to take part. We plan to submit the results of this study to academic journals focused on medical ethics so that research ethics boards can improve the experiences for kids and teenagers with chronic illnesses when they participate in medical research. What you have told us about your experiences with participating in research related to IBD will help future researchers design better studies.

If you have any questions about the results of the study please contact us. We would be happy to talk to you more about what we found. To get in touch with us, please contact **Kieran O'Doherty** at kieran.odoherty@uoguelph.ca or 519-824-4120 x 58919, or **Claudia Barned** at cbarned@uoguelph.ca or 519-824-4120 x 52104.

Sincerely,

Claudia Barned and Kieran O'Doherty