

## **Summary of Results:**

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

In general, most kids and teenagers that we interviewed found participating in research to be a positive experience. Some kids and teenagers talked about how it's fun and exciting to take part in research, especially when research involves activities like watching a movie or using an iPad. For example, one participant described participating in a study where she got to use an electronic tablet: "I thought the tablet one was really different because I was on a tablet and I was doing cool, like hitting cool buttons and I thought it was really cool." Other participants liked participating in research because they got to miss school. Lots of participants that we spoke to felt that taking part in research was "no big deal." For some participants that we spoke to, research seemed like a regular part of the visit to SickKids.

Not all the kids and teenagers that we spoke to enjoyed participating in research though. Some participants talked about how some studies that they had participated in turned out to be painful or uncomfortable. For example, one participant described participating in a study where a sample was taken from her nose: "They said they'd scrape the inside of your nose, and said, well it's not really a scrape, it's like a scoop. No, it was a scrape. I don't like things being shoved up my nose. I wasn't a fan of that study." Other participants talked about how it can be a bit boring to participate in research, and that participating in research can take extra time.

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

Kids and teenagers with CF (and their parents) had several reasons for choosing to participate in medical research. Many people we interviewed talked about participating to help other people with CF and to help find a cure or improve treatment for CF. Other participants chose to take part in medical research because the study sounded interesting or valuable, or they thought it might be fun to take part. Other participants chose to take part in studies because they thought they might personally benefit from the study. For example, some participants talked about participating in research to test a new medication or device (like a mask) that might help them. One participant said "Well I was open to anything. I was told that it might help me not cough as much so I'm like, hey if that'll do that then, I want to try it, give it a chance." Another reason for participating in research that many kids and adolescents mentioned was trust. Kids and adolescents talked about participating in research because they trusted the doctor or nurse who asked them to participate, or because they trusted their parents who thought participating was a good idea. Finally, many kids and adolescents said that participating in research was just something they do as a normal part of their visit to SickKids. These participants talked about not really considering their reasons for participating in research, it just seemed like a normal part of a visit to the clinic.

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

We also asked participants about their reasons for choosing not to participate in research. One of the most common reasons for choosing not to participate in a study was that the study would take up too much time, or they would have to come back to the clinic. For kids with CF and their parents, they often felt like they would like to participate in a study to help out, but they couldn't take any more time off school or work to participate. Another common reason for not wanting to participate in medical research that was mentioned by kids and teenagers was that the study involved a procedure that they didn't like. A lot of kids and teenagers mentioned that they didn't like having blood taken, so they would say no to a study where they had to have extra blood taken. For example, one participant described saying no to a study because she has a fear of blood tests: "One of the studies that I said, I think this was the only one that I said no to was like a good, you know, just come in for like a few blood tests a month and I'm like 'no way.'" A few participants also talked about not liking to take part in research because it is an extra commitment that reminds them of the fact that they have CF.

## **How Do Children and Teenagers With CF Decide Whether or Not to Participate in Research?**

We also asked participants to tell us about how they usually decide whether or not to participate in research. A lot of kids and teenagers that we talked to told us that they talked to their parents to figure out if they should participate or not. For example, one participant talked about how she and her parents made the decision to participate in research together: "It's mostly if my parents say it's ok and if I want to do it then I can do it." Other kids talked about talking to their doctor or the nurses at the clinic to decide if they should participate. Some participants made the decision on their own though, and didn't check with their parents. Other participants said that they would read the consent form and ask the researcher questions to figure out if they wanted to participate. All the participants that we interviewed said that they had never felt pressured to participate in research, and everyone we talked to said that they knew that they had a choice about whether or not to participate.

## **Conclusions**

Overall, we conducted interviews with 19 kids and teenagers with CF (and many 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 how they think about research versus treatment. These results show us that kids and teenagers with CF have many different experiences with research. Some kids like participating, whereas others don't – both of these are okay! Kids and teenagers felt free to decide whether or not they wanted to participate in a

study, and usually thought about whether the study would be helpful (to themselves or others), whether it would be painful or uncomfortable, whether they had enough time, and what type of procedure was involved before taking 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 CF 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](mailto:kieran.odoherty@uoguelph.ca) or 519-824-4120 x 58919, or **Jennifer Dobson** at [dobsonj@uoguelph.ca](mailto:dobsonj@uoguelph.ca) or 519-824-4120 x 53307, or **Emily Christofides** at [echristo@uoguelph.ca](mailto:echristo@uoguelph.ca) or 519-824-4120 x 52104.

Sincerely,

Kieran O'Doherty, Jennifer Dobson and Emily Christofides