

**BCCH – Child Sized KT
Focus Group Moderator’s Guide
FINAL
June 21, 2017**

INTRODUCTION and WARM UP (10 MINUTES)

- Welcome and thanks.
- Moderator introduction:
 - Purpose: talk about participating in research programs.
 - Focus group process: videotaping, meeting room, colleagues observing.
 - Confidentiality.
- My role:
 - I have a set of questions I want to go through, facilitate the conversation.
 - I want to keep you on topic and on time.
 - Make sure everyone participates and enjoys themselves.
 - If you normally are the first to speak, please allow time for others to speak as well. If you normally sit back in a conversation, I'd like you to make an extra effort to speak up.
 - Respectful listening – do not interrupt, allow people to finish.
- The rules:
 - Cell phone off.
 - Be as open, honest and descriptive as possible.
 - One person speaks at a time, no side conversations.
 - Speak loudly and clearly.
- To start, please introduce yourselves: tell us your first name and a little bit about you – where you live, what you do for a living, who lives in your household with you and what your family's top priority when it comes to the health of your children.

WILLINGNESS TO PARTICIPATE & POTENTIAL BARRIERS (30 MINUTES)

- First off, who can tell me what a health-related research project might look like?
 - What might be involved?
 - What might it be trying to achieve?
 - How would parents or children participate?
 - What would happen with the results?
 - Who has participated in a health-related research project before? What was it related to?
- MODERATOR HAND OUT SIX STEPS – There are six steps to a typical research program.
 - Identify the problem
 - Develop the questions
 - Design the study
 - Collect the information

- Analyze and interpret the information
 - Share the results
 - MODERATOR TO READ OUT EXAMPLE TO EXPLAIN
 - Looking at these six stages, which stages do you think your participation or input might provide the most value?
 - Why? How?
 - Which stage(s) do you think you would be most interested in participating in?
 - Why?
 - PROBE: So as you can see, there is an opportunity to participate so that you not only provide data and information for the actual study but you can also shape the purpose and outcomes of the research – what it is trying to do, etc.
 - How important is it for you to help shape what the research is trying to achieve?
 - How about sharing of the study results? How important is it for you or other participants to help share the results of the research.
- Now that we've expanded our understanding of what research projects look like, would you be interested in participating in a child-focused, health-related research study if you were approached?
 - If Yes, why?
 - If Not, why not?
 - Probe as appropriate:
 - The research study is too far away (distance)
 - Time commitment required
 - Having to drive to the hospital to participate in the study
 - Concern about my child's/children's privacy
 - Don't think my child/children will want to participate
 - The research study commitment is too long
 - A research study that addresses an issue that's not important to me
 - Concern about the accuracy of the results
 - Concern about the importance of, or need for the research
 - Working with a research team who I'm not familiar with

OPENNESS/BARRIERS TO ENGAGING ONLINE & COMMUNICATION (50 MINUTES)

- We have been discussing the various stages of research studies and now I want to explore how you feel you might want to engage in those research phases in an online environment.
- I want to focus on four functions that this future website might be able to facilitate:
 - **Connecting** with you - such as informing you of potential studies to participate in.

- Providing an **online community** for parents to engage with each other and with health researchers, so that research meets the needs of parents/ patients
- **Collection** of data
- **Sharing** the information and knowledge that may be helpful for managing your child's health including informing you on newly completed studies
- First of all, let's discuss **connecting** with you – in other words how an online health research environment might communicate with you.
 - (All/Most) of you mentioned you were interested in participating in potential studies. What would be your preference for being informed about potential studies that you may want to participate in?
 - How would you like to be informed?
 - Probes: email, social media, phone call, text message,
 - Would you be willing to register on a secure website to indicate your interest in participating?
 - If not, why not?
 - If you are willing to register on a secure website would you be willing to indicate the types of studies you would like to be informed of?
 - If not, why not?
 - If you are willing to register on a secure website would you be willing to provide profile information such as child's age, gender, etc.?
 ▪ PROBE: How about providing details on your child's health history
 - Would you be willing to provide your ideas or thoughts on what research questions are important to you?
 - How?
- Now let's discuss **collection** of data
 - So let's assume that there is a secure online website on which you have agreed to participate in a study
 - How do you feel about answering questions or providing information on your child's behalf and submitting those questions on a secure website?
 - If this makes you uncomfortable, why? What are your concerns?
 - What would need to be in place to make you more comfortable?
 - Now imagine as part of a study you are required to document your 'lived health experience' (for example through photos, videos, stories). How do you feel about answering questions or providing information through photos? How about videos?
 - If this makes you uncomfortable, why? What are your concerns?
 - When do you think it might not be appropriate for a study to be conducted online?
 - When might telephone or in-person be more appropriate?
 - Can you think of any other issues or barriers to you participating in a study using an online tool/website?
- Now, let's talk about **sharing** of information and studies
 - How do you currently search for, or keep up to date on, health related information for your child?

- MODERATOR CREATE LIST ON FLIPCHART
- What have you found are the best online resources?
 - Are you finding what you are looking for?
 - Do you feel the right information is available? What is missing?
 - What is the best resource to keep up to date? (versus searching)
- If BCCH posted the results of the research studies it conducted would that be useful?
 - Would you use this as a resource – why, why not?
 - How would you like that information organized?
 - How would you like to be notified that new information is available?
 - Would you share this new information/findings from a study with others in your network? If yes, how?
- Lastly I want to explore **online communities** you may be involved in.
 - Are you a member of any parenting or health-related online group on Facebook or any other network or website?
 - If so have they been useful? How?
 - If not, why aren't you? Are they not useful?
 - What type of device do you tend to access this? Computer, phone, tablet?
 - If BCCH provided an online community where you could connect with other parents concerned with their children's health including sharing stories and information would that be useful?
 - If so, how?
 - If not, why not?
 - Would you use it?

If time

We've talked about a number of aspects of this potential online tool:

- What other functions or features should be on this tool that you as parents would find useful when it comes to your child's health?

CLOSING

Those are all the questions we have for you today. I'd like to thank everyone for their time. If you go out to the front office, you can sign for your thank you for your hard work tonight. [FOR FIRST GROUP] You'll notice there's another group of people waiting outside, so please don't discuss what you did in the groups tonight on your way out.