**Guide for LLAH patient and family interviews**

*Note: Interviews will be conducted in a semi-structured manner, therefore the following are questions and prompts that may be modified in response to information provided by the participant. Participants will be reminded at the beginning of the interview that there are no right or wrong answers, that interviews will be recorded, that direct quotes may be used in the research paper but they will be de-identified (i.e., no names or identifying details will be reported), and that they are free to skip any questions or stop the interview at any time.*

*Interviewer will start by providing an overview of the LLAH (emphasis on child health research that is conducted using daily experience measures in the community) and a “typical” LLAH study, to remind participants of what could be involved (including the EMA, accelerometer, salivary biomarkers).*

**Demographic questions**

**Parent:** Age: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Sex (circle): Male Female

**Child/Youth**: Age: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Sex (circle): Male Female

Ethnicity: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Language spoken at home: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Child/Youth comorbid diagnoses: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Semi-structured interview questions**

1. What do you think about the LLAH study idea?
2. If there was an opportunity, would you participate in a LLAH study?
   1. Is there any part of the LLAH study that you wouldn’t want to participate in?
3. How long do you think you could participate in that kind of study for? (e.g., 1 week? 1 month?)
   1. Would this change if there was a break period? (e.g., 2 weeks with a 1-week break in the middle)
4. What do you think is a fair amount to pay people to thank them for participating in a LLAH study?
5. Are there any barriers that you think would make it hard to participate in a LLAH study?
   1. What would make it easier for a person like you to participate in a LLAH study?
6. Now I will ask some questions about one of the data collection tools in the home: the smartphone reported Ecological Momentary Assessment (EMA):
   1. What types of questions should we be asking about (e.g., experiences, symptoms, emotions, social interactions, sleep) that would help us understand how your day is going and what parts of your day are important to you?
   2. How many times a day would it be reasonable to ask you to fill out questions?
   3. Would there be anything that would get in the way of you being able to answer questions using a smartphone?
7. Would you have any concerns about the privacy of your data in participating in a LLAH study?
8. Would you want to have access to your data when doing a LLAH study?
   1. What would you want that to look like? (e.g., All responses? Charts or graphs of daily changes? Summary reports? Alerts?)
   2. What would you do with that information?
9. What are some of the important questions you think we should be using this type of research to answer?
10. What would be the best way to reach families to let them know about the LLAH and invite them to take part? (e.g., clinics, social media)
11. Do you have any other questions or ideas, or anything we haven’t talked about that we should have?

**Guide for LLAH patient and family interviews: SNI sub-study**

*Note: Interviews will be conducted in a semi-structured manner, therefore the following are questions and prompts that may be modified in response to information provided by the participant. Participants will be reminded at the beginning of the interview that there are no right or wrong answers, that interviews will be video-recorded, that direct quotes may be used in the research paper but they will be de-identified (i.e., no names or identifying details will be reported), and that they are free to skip any questions or stop the interview at any time.*

*If the child/youth is taking part with the parent, they will be encouraged to participate by communicating in whatever way is comfortable for them. This may include gestures, assistive communication devices, having the parent respond/interpret on their behalf, etc.*

*The interview will be adapted in whatever way is needed e.g., simplifying questions, having parent reword the question in a way they can understand, having questions printed, etc.*

*Interviewer will start by providing an overview of the LLAH (emphasis on child health research that is conducted using daily experience measures in the community) and a “typical” LLAH study, to remind participants of what could be involved (including the EMA, accelerometer, salivary biomarkers)*

**Demographic questions**

**Parent:** Age: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Gender: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Ethnicity: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Child/Youth**: Age: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Gender: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Ethnicity: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Language spoken at home: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Child/Youth diagnoses: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Semi-structured interview questions**

1. What do you think about the LLAH study idea?
2. If there was an opportunity, would you participate in a LLAH study?
   1. Is there any part of the LLAH study that you wouldn’t want to participate in?
3. How long do you think you could participate in that kind of study for? (e.g., 1 week? 1 month?)
   1. Would this change if there was a break period? (e.g., 2 weeks with a 1-week break in the middle)
4. Are there any barriers that you think would make it hard to participate in a LLAH study?
   1. What would make it easier for a family like yours to participate in a LLAH study?
5. Now I will ask some questions about one of the data collection tools in the home: the smartphone reported Ecological Momentary Assessment (EMA):
   1. Who would be the best person to fill this out? (e.g., child, parent, other caregiver, child providing answer to parent and parent completing it on their behalf)
   2. What types of questions should we be asking about (e.g., experiences, symptoms, emotions, social interactions, sleep) that would help us understand how your day is going and what parts of your day are important to you?
   3. How many times a day would it be reasonable to ask you to fill out questions?
   4. Would there be anything that would get in the way of you being able to answer questions using a smartphone?
   5. Is there anything that would make it easier to answer questions using a smartphone? (e.g., having the option to fill it out on a computer/paper instead)
6. Are there other types of data collection that you think would be useful to understand your own family or child?
7. What do you think is a fair way to compensate families to thank them for participating in a LLAH study?
   1. If we are asking your child to participate in a study like this, what might be rewarding for them or help encourage them to do it?
8. Would you have any concerns about the privacy of your data in participating in a LLAH study?
9. Would you want to have access to your data when doing a LLAH study?
   1. What would you want that to look like? (e.g., All responses? Charts or graphs of daily changes? Summary reports? Alerts?)
   2. What would you do with that information? (e.g., who might be useful to share it with?)
10. What are some of the important questions you think we should be using this type of research to answer?
11. What would be the best way to reach families to let them know about the LLAH and invite them to take part? (e.g., clinics, social media)
12. Do you have any other questions or ideas, or anything we haven’t talked about that we should have?