

Supplemental Table I. Code Book

Category	Subcategory	Code
<p>General barriers to health related research</p>	<p>General Mistrust of Studies</p>	<p>“The phrase clinical trial makes me think of the Tuskegee experiment .” “With research I always picture an animal, of course, and it puts a little cringe in your body when you hear that term” “If they use “research”, I’m like no” “Clinical Study seems like a study instead of being tried out as a guinea pig.” “I kind of get on edge when it’s anything to do with a research study.” “Like they say using someone as a guinea pig, that’s how I felt” “I don’t think it’s just any trial; it’s a trial involving medication. It’s scary.” “I would rather wait until the study was over.” “My issue isn’t how my child is chosen, I just wouldn’t want to go into that situation.” “I probably wouldn’t be in favor of it because it’s still something that’s being researched. I would be more comfortable if it was a closed study that they said was going to help.” “I would be more open to clinical trial than research. There are a lot of questions with research, like you don’t really know if this is going to work.” “Research and clinical trials are both very scary” “Basically whenever you say research or clinical trials, I cringe. I don’t want my child to be poked and pricked or be the guinea pig.”</p>
	<p>Emotional Issues</p>	<p>“You are asking me to take my normal child and put him through a through a trial. In my mind that’s more needles and more poking and prodding. It’s not me. If it were me I would do it to help someone else but it’s my child and I am supposed to protect him.” “She has enough with the needles and stuff so I don’t want to put her through any more than what she has to go through” “I take in to consideration our child, because emotionally it affects him when he comes; the wait and the anxiousness of having lab work done, which is a part of his life, but he now connects going to the hospital with getting stuck with needles and so you have to deal with the dramatic, emotional distress with the child which causes stress with the parents. Until he started having issues, we were more comfortable saying no because we didn’t want him to go through the traumatic experience.” “If he sees someone in a white coat coming at him he asks them if they’re going to hurt him.”</p>
	<p>Practical Issues</p>	<p>“I think a good thing would be after hours.” “I don’t really want to do it if (I have to come to clinic more often)” “Who has time to be running back and forth?” “Plus wasting gas driving down here” “Having too many x-rays could cause certain number of issues so how would having MRIs affect his body?”</p>

<p>Randomized Trial</p>	<p>Medication vs. Placebo</p>	<p>“Adults are more prone to taking medications than parents are to giving them to their children.”</p> <p>“What would make me not interested is something they just came up with, like my child would be the first one.”</p> <p>“I think the drug plays a huge role, which goes back to what I was saying before; I would be more interested in my child not taking a drug in a study”</p> <p>“I think I would be interested in entering my child in a study or trial if she was in the group that didn’t have to take the medication. I don’t think I would be interested if it was the other way around or if there wasn’t a whole lot of information that I knew about and feel comfortable with her participating. I would be real cautious.”</p> <p>“I don’t feel as comfortable with that because if I’m agreeing to be in a trial, it’s because he needs it and I don’t want to risk that he doesn’t get the treatment. If I’m going into a clinical trial I want to be sure he is given the medication.”</p> <p>“If it were my child I would want him to have the real thing that could help him.”</p> <p>“Why would we want to put your child on a clinical study when he is fine and he may possibly get the actual medication and end up with the side effects?”</p>
	<p>Rationale</p>	<p>“I know this trial and error thing with research is ongoing but I just want something that is grounded, more secure.”</p> <p>“It would be a waste of time when we could be finding something that actually worked instead of playing a yo-yo game with my child’s life.”</p> <p>” If you know the procedure is going to work then you are more likely to be a part of it. As opposed to going and something good might happen for my child but just to go and nothing happens that I feel to better the situation with my child or to understand his illness.”</p> <p>“I’m not too thrilled about it because what she was saying, how do they choose?”</p> <p>“Some children have more severe problems and I feel like they should scratch out randomized and sit down and think would this medicine help this child?”</p> <p>“I wouldn’t want my grandson to be in a clinical study and be in pain and not be getting what he needs. If everything was normal for a sickle cell child I would go with the clinical study because if anything changed while he was in the study I’m sure they would pull him out and give him what he needs.”</p> <p>“ If your child is fine from a sickle cell standpoint, not having issues, that’s one thing going into a blind study but if your child is already having crises and issues...”</p> <p>“What I don’t understand is that if this medicine is going to increase the fetal hgb then why is a trial needed?”</p> <p>“Is there any study data? If it would benefit I would rather know now. There has to be some data now that says, “this number of patients have been on HU for so many years.” We don’t want our child having pain and if there’s a way to prevent it then I’m all in it. I don’t ever want him to feel pain but is a clinical study the best way? If it’s a blind study he may get the placebo which means he’s going to keep having pain.”</p>

Hydroxyurea	General	<p>"If they told me she had a silent infarct or was at risk for one, I would still want to find out more about HU before they put my child on"</p> <p>"I'm just real cautious. I've heard the name HU but don't know much about it and that's what concerns me."</p> <p>"Giving it to a child that is too young to express where it hurts."</p> <p>"All of them really" (barrier to hydroxyurea)</p>
	Unknown long term effects	<p>"With HU, the thing is I'm concerned with the long term effects of the drug. That's my biggest hesitant. He's fine now but how is it going to affect him long term."</p> <p>"Mine (my barrier) would be the long term side effects"</p> <p>"It sounds really good right now but how will it affect my child when he's older? I know there may not be a way to know all those answers but that would be what would weigh in on my position"</p> <p>"What I want to know if there are any long term side effects."</p> <p>"That is one thing I am concerned about just because it's not known. That's the part that gets me, the unknown."</p> <p>"The long term side effects are not known"</p>
	Acute side effects	<p>"How will that affect them going to school and being able to enjoy life"</p> <p>"They say rash and skin darkening are side effects but what causes that side effect? The rash? What is it and what does it need to be treated with? Is there something in it that could hurt my child?"</p>
	Cancer	<p>"You hear of people who have cancer or illness related to a medication. That's the part that makes me really cautious"</p> <p>"Cancer mostly."</p> <p>"Anything big like the cancer."</p> <p>"I did read something on the internet that said something about leukemia."</p> <p>"As of now my child doesn't have cancer but what about when my child is older and develops cancer cells and it is somehow related to HU"</p>

Facilitators	Peer support	<p>“Group sharing their experiences with their children and seeing what they go through and getting their feedback helps a lot.”</p> <p>“I’m looking to really connect with others who are walking the walk. We do our research and listen to the professionals but when it comes to your child and their journey in their life and being responsible for them until they reach a certain age of independence, it’s a matter of connecting with the individuals who I can sit down with and hear them talk and pick up on their emotions and hear what their child has gone through without them trying to sugar coat or making it sound like it’s so easy to be accepted. As much as we love our doctors, it’s the connection with other parents.”</p> <p>“My experience at the meetings at the Sickle Cell Foundation where the families would get together to share their experiences.” (wanting peer support)</p> <p>“More comfortable; I think more support groups, which of course you have to keep confidentially, but connecting with a group of individuals with sickle cell disease and discussing your concerns helps. We connect better with individuals who are going through the same thing.”</p>
	Education	<p>“I would want to know more.”</p> <p>“I would want more information on it.”</p> <p>“I wanted to come because this is concerning my child and if there is anything you can do or offer, I’m all for that. I just wanted to learn about what the silent stroke is and see how I feel after the group.” (I want to learn) “because it’s for my child’s well being.”</p> <p>“What would make me interested if I knew that had already done as much research as they could and make sure it’s safe for my child.”</p> <p>“If they found out something through the study, I would be one of the first people to find out about it.”</p> <p>“I might would consider it once I had more information.”</p> <p>“I’m happy when I hear about it; to know that there’s research.”</p> <p>“As long as I know my child is safe and I can learn more of the side effects and know that it is a harmless procedure.”</p> <p>“If I researched more about it, I may be more comfortable considering it.”</p> <p>“The only thing you could do is give me information. I don’t know if there’s anything you could say to convince me at this point.”</p> <p>“I just want more information. Why was this medicine chosen? Who did the research to say this medicine is going to help my child? What about the long term side effects? Is something going to be severely wrong with my child from taking this?”</p> <p>“With this being such a serious situation there may not be a whole lot you can say to influence a parent to give the medication just because there is so much you have to weigh. The information that you have is <i>all</i> you have to give. You don’t have all the answers to the questions that a parent may have. Because you don’t have all the answers you are limited in having that impact to have a parent say I trust what you are saying, let’s give my child this medication. I appreciate you guys being so honest about what you do know and what you don’t know and it makes me trust the staff a lot more and be able to really consider what you are saying.”</p> <p>“If you give me more information up front I’m going to be more likely to participate. The doctor may know all along that we have the right to get out of this but unless you tell me, how am I going to know.”</p> <p>“I didn’t have a clue about them until I got the pamphlet in the mail and I read it and want to know more about it”</p>

<p>Facilitators con't</p>	<p>Education about rights during a trial</p>	<p>“I know it may be counter-productive to give that information up front because some people may just want to try it for a couple of days and get out but that gives me a little comfort with a study. I know that the doctors have the child’s best interest at heart but you want to hear, “ this is what we are going to do and if at any point you want to get out, that’s fine.” I know that sometimes that may be counter-productive because some might take that out sooner than others but just knowing that would make me more likely to participate.”</p> <p>“Is there an out when you’re in a study? That would be my concern. Not that you go in thinking you’re going to get out half way through but if you see things going south health-wise for your child, can you talk to your doctor and say.....”</p>
	<p>HU for SCI</p>	<p>“He would be taking the medication for a purpose not just for a trial.”</p> <p>“I’d rather him be on a trial instead of him taking the medicine when he really don’t need it”</p> <p>“I would want to know what to expect as a result from the silent stroke.”</p> <p>“(It’s) Scary, I wouldn’t know what to do.”</p> <p>“Just based on the knowledge that I’ve gained through the clinic here, that is probably one of the scariest things. I can watch my little one growing and gaining knowledge and I know what a stroke can possibly do to someone and that’s scary.”</p>
	<p>Extra Visits</p>	<p>“If our child was on a drug like HU, we wouldn’t have a problem with coming to clinic because he would be better off being monitored”</p> <p>“I would want to come (to clinic more often) just because I know it’s important.”</p>