

Supplementary 1. Interview guide

Adjustments that were made after the first round of interviews are shown in red.

General questions (1)

- How old is your son/daughter?
- Where was your son/daughter born?
- Do you have more children? How old are they?
- Do you have a relationship with the father/mother of your child? (Married, living together?)
- How is your child doing?

Experiences and needs – past

- When was the first time you noticed there were problems with the development/health of your child? What did you notice? How did you deal with that? How did your family/partner deal with that?
- When was the first time you visited a doctor for these problems? Why did you decide to see a doctor at that moment? How did it go?
- What were your expectations of the doctor?
- Were you eager to know what the cause of the problems was? Why (not)? What did you do to find out the cause? (Visit doctors/other people)
- What did you think was the cause of the problems of your child?

Experiences and understanding – diagnosis

- Do you know now what the cause of the problems of your child is?
- What do you know about what your child has? How do you know this?
- Who told you what your child has and how did that go?
 - Who else was present at that moment? (Partner, children, intern, interpreter?) What did you think about them being there?
 - Were there any specific comments the doctor made that you remember?
- What was your first reaction when you found out what your child has? How is that now?
- Do you feel it took a long time before the doctors knew what your child has? How was that for you?
- ~~What does it mean for you~~ Was it useful for you to know what your child has?
 - What were the consequences for you or your child when you knew what your child has?
 - Did something change in the treatment after knowing what your child has? (For example: other support, more/less visits to the doctor, other school, referral to other specialist)
 - What kind of help/care does your child get now?
 - Are there negative sides about getting a genetic diagnosis?
- If you could go back in time, would you choose again to do the test?
 - Would you have liked to know the diagnosis earlier?
 - If you would have gotten the diagnosis earlier, what would have been different now?
- What do you expect for the future? And for your own role in it?
- Are there still questions that you have now?
- What are things that are difficult for you now?
- Do you know what the consequences are for your other children/if you want to have other children? Can you tell something about that?
 - Did it have any influence on your other children? (Worries about their health, genetic testing, but also impact on other children)

- Did it influence your choice to have more children? Can you tell more about that?
- Did you think about possible options if you want to get pregnant again? Can you tell more about that? What options are there? Why would/wouldn't you choose for that?
- Do you know if there are consequences for your child if he/she wants to have children later?

Satisfaction with genetic services

- ~~Did you get sufficient information about what your child has? From whom did you get this information?~~ How was the consultation with the clinical geneticist?
 - What was good about it?
 - What could be improved?
 - Did the doctor use language that you could understand?
 - Were there enough possibilities to ask questions?
 - Did you get any written information to take with you? Or a referral to a website?
 - Did you have any unanswered questions?
- Did you look up information later on the internet? What did you think about this information?

Experiences and needs – surrounding

- Did you talk to people in your surrounding about what your child has? With whom? How did that go?
 - How do people in your family treat your child?
 - How do other people in your surrounding treat your child? (School, neighbors, friends, etc.)
 - Do people in your environment treat your child different now that they know what he/she has?
- Are there enough possibilities here to provide the care that your child needs? Why (not)? What is missing?
- Did you ever consider moving to the Netherlands for your child?
- Did you try to get in touch with other parents or an association of parents that have a child with the same condition? Is this something you would want? Did the pediatrician/clinical geneticist point out any possibilities for this?
- To what extent can you pay all the cost for healthcare? Did that change after knowing what your child has? What is (not) covered by the healthcare insurance? Which healthcare insurance do you have?

General questions (2)

- How old are you?
- What is your job?
- What is the highest level of education that you finished?
- Where were you born?
- Where were your parents born?
- Are you religious? If yes: which religion and how active are you in this?

Final questions

- Is there anything you would like to add?
- Is there anything else you would like to say?
- How was it to participate in this interview?