

Supplemental information: Interview guide

First, thank you for volunteering take part in this study. I would like to emphasize that your participation is voluntary, which means that you can stop at any time, feel free to ask for clarification, and/or decide not to answer any or all of the questions.

This interview includes questions about you and your family and obsessive-compulsive disorder. You will also be asked to listen to two short stories and to provide your opinion about the information presented. If you have any questions or need anything repeated, please let me know.

[Part 1 - Demographic questions]

I'd like to start by asking a few questions about you, to get an idea of where you're coming from. Keep in mind that all the information you share with me today will be kept confidential.

- Are you the mother or father of the child?
- What is your current age?
- What is your ethnic background?
- What religion or spirituality practice, if any, do you identify with?
- Are you presently employed?
- What is your marital status?
- How many children do you have?
- Are there other individuals in your family who have OCD?

[Prompts:]

- How is this individual related to you?
- What are his/her symptoms?
- When and how was he/she diagnosed?

[Part 2 – Experience with OCD]

Thank you for sharing that information with me. Now I'd like to turn the focus to your child who has OCD. Can you tell me about [his/her] experience with obsessive-compulsive disorder?

[Prompts:]

- At what age did [his/her] symptoms begin?
- What are [his/her] symptoms like?
- How old is [he/she] now?
- How does obsessive-compulsive disorder affect your [daughter/son]'s daily life?
- Tell me about the strategies that you/your child use to manage [his/her] symptoms.

Parental adaptation to OCD: implications for genetic counseling

- How do people react to you and/or your child with respect to your child's diagnosis of OCD?

[Part 3 – Causal attributions of OCD]

I'd like to learn a bit more about your understanding of the causes of your child's OCD. Can you tell me about what, in your mind, caused your child to develop OCD?

[Prompts:]

- Can you tell me where this understanding comes from?
- Do you think these are the same factors that cause OCD for all affected individuals?
- How does your understanding of the causes of OCD impact how you feel about the chances for other family members to develop OCD?
- How has this understanding influenced your decisions?
 - o [If ask for clarification:] For some people, this may influence whether they choose to have their child take medication, the decisions they make about family planning, etc.

[Part 4 – Interest in/perception of genetic counselling]

Now I'm going to read you two different stories. The stories have a number of different pieces, so if you want me to repeat something, please let me know.

In these stories, [Susan/Tom] has a child with obsessive-compulsive disorder. [She/He] has questions about the cause of obsessive-compulsive disorder and is concerned about it happening again in the family. [Susan/Tom] goes to see a genetic counsellor. A genetic counsellor is a health care professional who specializes in helping families who have concerns about conditions that can run in the family. After each story I'll ask you to tell me how the information that [Susan/Tom] learned could be useful or why you think that it is not useful.

[Vignette 1:] [Susan/Tom] goes to a genetic counsellor **to learn what causes obsessive-compulsive disorder**. The genetic counsellor tells [Susan/Tom] that obsessive-compulsive disorder is caused by a mix of a person's genes and non-genetic things, like the environment that they live in. The genetic counsellor explains that there are many genes involved that may be passed down from both sides of the family. Some things in a person's everyday environment, like being exposed to viruses, also may affect the chance of getting obsessive-compulsive disorder. The genetic counsellor says that, while good parenting helps all children's development, parenting style does not cause, or prevent, obsessive-compulsive disorder. The genetic counsellor and [Susan/Tom] discuss the importance of finding signs of obsessive-compulsive disorder early and getting treatment right away.

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Tell me about whether you think this sort of information would be useful.

[Prompt:]

- What makes you think that this would be useful/not useful?

[Vignette 2:] [Susan/Tom] goes to the genetic counsellor **to learn about the chance that obsessive-compulsive disorder could happen again** in the family. The genetic counsellor takes a careful family history, and asks [Susan/Tom] questions about the mental health of family members. The genetic counsellor also asks about [Susan's/Tom's] own mental health. The genetic counsellor uses the family history information to estimate that there is about a 20% chance, which is the same as a 1 in 5 chance, that obsessive-compulsive disorder could happen again in a young person in [Susan's/Tom's] family. The genetic counsellor says that this chance might not be exactly right, but is probably close. She hopes the information can give [Susan/Tom] an idea of how likely it is that others in [her/his] family may develop obsessive-compulsive disorder.

Tell me about whether you think this sort of information would be useful.

[Prompt:]

- What makes you think that this would be useful/not useful?

Those are all of the questions I have for you today. Are there other things that you've thought of as we've talked about obsessive-compulsive disorder and genetic counselling that you'd like to tell me?

[Debriefing:] I'd like you to keep in mind that the stories you heard were made up. The chances given to the person in the story for obsessive-compulsive disorder to happen again in that family are also made up. The chance depends on many things that are specific to each family. If you are interested in a genetic counselling session, we can assist you with a referral.

Thank you for participating in this study. Do you have any questions or comments for me?

[Consent for member checking:] We may be interested in contacting some of the people who have participated in this study to clarify what they have said or to review our preliminary results with them to gather any further insights. Would you be willing to be re-contacted by me as part of this process?