

The PIRL PROJECT

Semi-structured interview guide and focus group questions

Date:

Time:

Interviewer name & location:

Interviewee name & location:

Position of Interviewee:

Approximate Length: (record how long the interview took)

Record any relevant details of the circumstances of the interview:

Aims of this study:

Thank you for agreeing to be interviewed/participate in this interview/ focus group discussion (FGD). I would just like to remind you that the purpose of the current study is to gain an understanding of the experience of individuals who are involved in research related to disability inclusive development, the inclusion of researchers who have disabilities on research teams, and how people are learning about DID research.

Secondary objectives include (1) providing shared research experience and data for the participants in the PIRL project and who attend the PIRL Institutes; 2) developing recommendations for the PIRL Project.

We recognize that there is a range of experience levels, and that you might have a lot of experience, or you might be new to DID research. Regardless of your level of experience, we are interested in your perspectives.

Interviewer to ensure that consent has been obtained.

Interview/focus group structure:

This is the general format I will be using today.

First, we will begin with Introductions and the consent process, which we have just done/will do in a minute.

Then I will ask some questions:

About your background, and some demographic information

Then some fairly broad questions about DID research, ICT use, and your involvement in research.

As we go through the broad topics, I will ask some specific questions that will depend on your responses to the broad questions.

At any point, please feel free to give specific examples and tell detailed stories from your experience. We believe that we have a deeper understanding of the issues if we have some very detailed and contextual stories. If I ask you for more details at any point, it is to get at the nuances and the complexity of situations.

When either our time is up, or it seems that we have exhausted what to talk about, we'll have an opportunity for final remarks and summary statements.

Finally, we can debrief the interview/FGD, and talk about how it went.

Do you have any questions before we go further?

Additional comment for focus group: The focus group will be between 30 and 60 minutes, and we will not have time to address all of the questions in this guide. Between us we will decide on what the most important topics are for discussion and allow the conversation to unfold in a natural manner.

Questions and Probes:

1. Please tell me/us about yourself.

Probes:

- Where do you work? What is your country of origin?

Please share as many “identifiers” about you as you would like to. For example, your gender, your ethnicity, your age or year of birth, and so on.

What is your job?

- Where do you work? How long have you worked there?
- What kinds of people (colleagues/clients/patients) do you work with?
- Please check the boxes that apply to you on this sheet. [Participant will be provided with the following list or can do it verbally]

For INTERVIEWS only: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

2. Do you have difficulty seeing, even if wearing glasses? a. No - no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
3. Do you have difficulty hearing, even if using a hearing aid? a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
4. Do you have difficulty walking or climbing steps? a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
5. Do you have difficulty remembering or concentrating? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
6. Do you have difficulty (with self-care such as) washing all over or dressing? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
7. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood? a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all

Our next set of questions is about Disability Inclusive Development.

8. Please describe what you understand DID to be.

Probes:

- If you were explaining to someone who was not part of DID, what would you say?
- Have you described DID to colleagues or friends? What did you say?
- Are there any aspects of DID that people might not understand if they were not part of it?

9. **How have you participated in research related to DID?** Yes/no/not sure

10. **Please tell me more about your involvement in research of any kind.**

Probes:

- what projects and studies have you been part of?

Do you have an explanation or definition of what would make a research project specifically a DID project?

How often did you participate?

How have you learned about DID research?

Did the nature or amount of participation change over time?

- Were you comfortable contributing to DID research?
- There is a lot of information to take in about DID and Research, how have you managed that?
- ADDED: How included do you feel in the PIRL project, the PIRL team?

11. **If Yes to No 9: Do you feel like you were part of a community when you are part of a research team?**

Probes:

Please describe one or more of the research teams that you have been a part of.

- What helped you connect with others?
- Have these feelings changed over time?

Do you know any of the others with your experience/interest?

ADDED – [ask here if not addressed above]: How included do you feel in the PIRL project, the PIRL team?

12. **Please take a minute to think of one story about DID research that you remember well.**
Please describe this story to me.

Probes:

- Why did this particular event stay in your mind?

- Did it have personal meaning to you?
- Do you think others remember this moment as much as you do?

For FGD: Does anyone else have a similar or different experience?

If it has not come up in the responses in this section, the interviewer will ask: “Over the past many months COVID-19 has changed many things. Is there anything you would like to say about the impact of COVID-19 on DID generally, or on you specifically?”

Let’s talk now about the benefits and challenges of ICT and assistive technologies in DID research.

13. How have you used ICT?

Probes:

Note: We will enter findings from the survey. For example, from the survey, we know that some people do not have good access to devices and internet. What is your impression of this finding (s)? Does it resonate/ring true for you?

[Will be repeated for key findings that we want to discuss].

14. What technologies do you use, and please explain how they assist you in your research work?

15. What other comments do you have about DID research, inclusion, ICT or any related topic that we have discussed so far?

Probes:

- What is the impact of people not supporting DID research?

16. Do you ever talk to others in person about your involvement in DID research? If yes, what do you say?

17. Has being a part of research studies had an impact on any of your work relationships?

If it has not come up in the responses in this section, the interviewer will ask: “Over the past many months COVID-19 has changed many things. Is there anything you would like to say about the impact of COVID-19 on how ICT is used in DID?”

Lastly, we would like to know about what could be done in future to improve ICT, assistive technologies, DID research, inclusion on research teams, and so on.

18. What recommendations do you have for future research teams regarding how to best be inclusive?

Probes:

- What did you want from previous research teams that perhaps you did not get? (if not addressed earlier)
- If you were going to organize a DID research team, what would you do differently? What would you keep from your previous experience?
- What advice do you have for future researchers and team leaders?
- What comments do you have about the time commitment needed?
- How do you feel about the number of topics discussed?

19. ADDED: Some people in the project are very aware of the impact of their family (e.g. parents or the family they grew up with when they were a child). Would you like to say anything about your family, the impact of your family on you as a researcher?

19. Is there anything else you would like to share?

20. Do you have any questions about this study that you would like to ask?

21. Please reflect on this interview/focus group discussion and briefly summarize one or two key points that you would like us to emphasize when we write up this process.

When the interview/FGD is completed, the interviewer should thank the participant(s).