

# Qualitative Researchers' Handbook

COVID-19 & Disability: A multi-country study

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## Using this resource

Any use or adaptation of this handbook should be cited as follows:

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## 1. *Research overview*

This research will focus on disability and COVID-19. This study involves multiple countries, including Zambia, Turkey (Syrian refugees in Istanbul), Ghana, India, Zimbabwe and Bangladesh.

The overall aim of this research is to explore the experiences of people with disabilities during the COVID-19 pandemic. For example, it will look at:

- The effects of the COVID-19 pandemic on the health of people with disabilities, including their mental health, and ability to access needed ongoing healthcare (e.g. rehabilitation, psychiatry, chronic illness management).
- The economic effects of the COVID-19 pandemic (e.g. on livelihoods, food security, income) amongst people with disabilities.
- Other impacts of the COVID-19 pandemic on the daily lives of people with disabilities (e.g. social life, access to social care and other key services).

It will also consider the extent to which people with disabilities are included in response activities. For example, we will:

- Assess knowledge and opinions of COVID-19 and direct response measures (e.g. social distancing, hygiene, access to vaccines) amongst people with disabilities.
- Identify strategies used by stakeholders (e.g. DPOs, NGOs, relevant government department and global agencies) to include people with disabilities in responses to the COVID-19 pandemic (i.e. prevention, treatment, and interventions to mitigate the health, social and economic impacts) and explore their strengths and weaknesses.

To gain information on these topics, we will interview adult and children and different types of disabilities. Each interview is expected to last approximately one hour. These interviews may be done either by phone or in-person, depending on the participants' preferences and COVID-19 guidance at the time of data collection.

## 2. *Overview of interview process*

### 2.1. *Pre-interview (see section 3 for more details)*

- **STEP 1:** Call the person with a disability. Make sure you're talking to the person with a disability and not another household member, unless the participant is a child (below national age of consent) or a person with a disability who has severe difficulty understanding (even then, try to verify for yourself).
- **STEP 2:** Describe the study and what will be involved if they choose to participate. Offer to read the information sheet or email it to them.
- **STEP 3:** Ask if they are interested in being interviewed. If they are, ask about any adaptations needed (e.g. sign language interpretation). Determine if a proxy interview with a caregiver is needed.

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### 2.2. Day of interview (IN-PERSON INTERVIEWS)

- **STEP 4:** Arrive at the meeting spot (in-person interview). Introduce yourself and briefly explain your purpose to anyone who is present/wants to listen.
- **STEP 5:** Find a quiet place to talk where the participant is comfortable. Make sure the place is private. Stop others from joining the interview unless needed for communication assistance (e.g. sign language interpreter) or else requested by the participant.
- **STEP 6:**
  - Adult participant: Read the information sheet to the participant or give it to them to read. Encourage him/her to ask questions.
  - Child (below age of consent) or adult participant with difficulty understanding/communicating: Read the information sheet to the participant's caregiver, or give it to them to read. Encourage him/her to ask questions. If the child/adult with a disability will participate a bit in the interview, they must also provide their consent.
- **STEP 7:** If the participant agrees to participate, he/she must sign or thumbprint the consent form. You cannot go forward with the interview unless you have consent.
- **STEP 8:** Start the audio recorder.
- **STEP 9:** Conduct interview. Keep in mind:
  - Ask follow-up questions! The interview guide is just a guide – it should not be treated like a questionnaire.
  - Take notes of what the respondent is saying and any other details of surroundings (e.g. any interruptions, the setting)
  - Maintain privacy. (Politely) ask anyone who comes by to leave.
  - For child interviews, you may wish to conduct some or all of the interview with the child alone.
- **STEP 10:** When discussion is finished, turn off recorder. Thank participant for his/her time.

### 2.3. Day of interview (PHONE INTERVIEWS)

- **STEP 4:** Make sure you are in an area with good phone/internet reception and that is quiet and private. Make sure you are equipped to record the interview and your equipment is functioning properly.
- **STEP 5:** Call the participant. Confirm you are speaking with the participant and not another household member (unless you are conducting a caregiver interview). Introduce yourself.
- **STEP 6:**
  - Adult participant: Read the information sheet to the participant. Encourage him/her to ask questions.
  - Child (below age of consent) or adult participant with difficulty understanding/communicating: Read the information sheet to the participant's caregiver. Encourage him/her to ask questions. If the child/adult with a disability will participate in the interview (even if only for a few questions), you should read them the simplified information sheet.
- **STEP 7:** If the participant and/or their caregiver agrees to participate, he/she must give oral, recorded consent (everyone who will be answering your questions).

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- Start the recorder. Read out the consent form and ask the participant to confirm their agreement by stating their full name and date. Stop recording and save the recording using their ID number. You cannot go forward with the interview unless you have consent.
- **STEP 8:** After you have recorded consent, restart the audio recorder.
- **STEP 9:** Conduct interview. Keep in mind:
  - Ask follow-up questions! The interview guide is just a guide – it should not be treated like a questionnaire.
  - Take notes of what the respondent is saying and any other details of surroundings (e.g. any interruptions, the setting)
  - Maintain privacy. (Politely) ask anyone who interrupts the call to leave.
- **STEP 10:** When discussion is finished, turn off recorder. Thank participant for his/her time.

### 3. Setting up interviews

#### 3.1. Contacting participants

You will be provided with a list of people to interview. The lists will look similar to this:

1.	2.	3.	4.	5.	6.	7.	8.
Name	ID	Gender	Age	Disability type	Phone	Agrees to participate?	Adaptations needed?
John	013	M	20	Intellectual	XXXXXX		
David	014	M	35	Hearing	XXXXXX		
Mary	015	F	47	Physical	XXXXXX		
Sarah	016	F	82	Physical	XXXXXX		

Column 1 tells you the name of the person with a disability. Column 2 provides an ID number that you will use in place of the participant's name when storing their information. Columns 3-5 provides information about the person and Column 6 provides their contact detail. You will fill in Column 7 and 8 based on your call with the participant.

In Column 7, you will record if you were able to reach the participant and if they agree to participate in the interview. You should call the participant at least 3 times at different days or times of the day before reporting that they are unreachable. If the participant refuses to participate, you should note this down.

In Column 8, you should note down any adaptations that the participant requires. This can include the use of a sign language interpreter, sending written versions of the questions over or using a simplified interview guide. You should also note down here if the caregiver will be involved in the interview (either with or without the participant with a disability).

Below is an example of how to complete columns 7 and 8:

1.	2.	3.	4.	5.	6.	7.	8.
Name	ID	Gender	Age	Disability type	Phone	Agrees to participate?	Adaptations needed?

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John	013	M	20	Intellectual	XXXXXX	Yes	Caregiver interview needed
David	014	M	35	Hearing	XXXXXX	Yes	Need sign language interpreter
Mary	015	F	47	Physical	XXXXXX	Participant refused	
Sarah	016	F	82	Physical	XXXXXX	Couldn't reach after 4 calls	
James	017	M	12	Vision	XXXXXX	Yes	Will do interview with caregiver and child

### *3.2. Who do you interview? Who can be present?*

The participant list tells you the name of the person with a disability. You should always try to interview the person with a disability directly. Section 7.2 describes adaptations we can use to support the participation of people with different types of disabilities.

In some cases, we may need to interview a caregiver of a person with a disability, either in addition or instead of the participant. There are two instances when we can use a caregiver interview:

- 1) **Children who are minors (below the national age of consent):** You will always need parental/guardian consent for minors. However, you may choose to interview either the child alone, guardian/parent alone, or both child and guardian/parent. Who you interview is up to your judgement as the interviewer, but as a general rule, you can interview the guardian/parent alone for interviews with young children (e.g. <10 years). For children who are 10+ years, you should try to get their direct input for at least some of the questions (e.g. on experience in school, mental health). Children who are more mature/independent may answer more/all the questions on their own. If you're unsure what the child can/cannot answer on their own, you can start by asking the child the questions. You can then ask the caregiver about questions they were unable to answer or where you think further information could be helpful. If interviewing the child (even if also interviewing the caregiver), it's recommended that these interviews are done separately (i.e. first talk to the child, then talk to the caregiver - without the other one present) so that they can speak freely.
- 2) **Adults with a disability who have severe difficulties understanding or communicating even with the adaptations we have available:** When possible, always try to verify the person with a disability's abilities yourself, as sometimes other household members can underestimate them. For example, ask to speak to the person with a disability and see if they can answer basic questions, like "What is your name?", "How are you today?". You should still interview the person with a disability directly even if you are only able to ask some of the questions or get limited responses, which can then be supplemented by a proxy interview for more detail.

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All interviews involving caregivers should be with the participant's main caregiver. **Caregiver means the person who spends the most time on a daily basis with the person with a disability or who knows the most about their experiences in daily life.** You should ask who is best suited for this role. The caregiver is often NOT the head of the household.

For all interview, **you should maintain privacy between you and the interviewee.** No one else should be present during the interview, unless specifically requested by the interviewee or if needed for communication (e.g. sign language interpreter). Before beginning the interview and when you are alone with the participant say "We usually do these interviews with just the two of us. However, if you would prefer someone else to join – for example, if this would make you feel more comfortable - please let me know." Only allow others to join if specifically requested (and then, only the requested individual).

**If other people come by, ask them politely to leave.** You can explain that you must follow the study protocols and are unable to continue if other people are present. Do not ask the participant if they mind them staying – this might make them feel pressure to say yes. Stop speaking if they don't leave, which will usually encourage them to move away.

### *3.3. Where do you conduct the interview?*

*Phone interviews:* Find a place where you have good internet or phone connection, that is quiet, and where you won't be overheard by others. Ask the interviewee to do the same.

*In-person interviews:* Find a quiet place where you can speak to the person privately. You can ask the participant where they recommend and feel most comfortable. You want to find somewhere where people cannot overhear you. For interviews with children, you should pick somewhere that others can see you, but not hear you (e.g. separate room with door open; outside).

## 4. Informed consent

### *4.1. What is informed consent?*

In order to participate in the study, all study participants must provide their **informed consent**. Informed consent means that they understand exactly what it is they are agreeing to do and what are the risks/benefits.

To help the participant decide whether or not they want to participate in this study, they need to be given or read the "Information Sheet". Please note, there are different information sheets and consent forms for children and adults.

Key points to highlight during the consenting process include:

- Their participation is completely **voluntary**: nothing good or bad will happen to them if they choose to participate or if they choose not to
- We **cannot offer benefits** to specific individuals for participating (e.g. cash, other forms of compensation, preferential access to any programme). Their responses however, will be helpful in planning policies and programmes that can benefit many individuals.
- The participant is free to **stop the interview** at any time, for any reason.
- Participant can choose to **not answer any question** at any time, for any reason.

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- All information disclosed will be kept **CONFIDENTIAL**.

It is important to encourage participants to ask any questions if they are unsure.

### **KEY POINTS ABOUT CONSENT**

- Before you begin any interview, you **MUST** receive informed consent
- Consent is taken **BEFORE** starting any interview. You **CANNOT** start without it or get consent later.
- All interviews with children below the age of consent (based on national definition) **REQUIRE** parental/guardian consent, even if you are not interviewing the parent/guardian. You also need the child's assent if they'll be answering your questions.
- If you do not get consent, you **CANNOT** interview the person
- If you are unsure if the person with a disability has fully understood the consent procedures, get consent from their carer as well

### 4.2. Who do you need consent from?

You need consent from anyone you are asking questions to. You also need caregiver/guardian consent for minors and for people with difficulty understanding/communicating.

<b>Category</b>	<b>Who do we need consent from?</b>	<b>Who do we interview?</b>	<b>What forms do we use?</b>
Child with a disability (age <10 years)	Caregiver only	Caregiver only	Standard information and consent sheet (filled in as a caregiver)
Child with a disability (age ≥10 years but below age of consent)	Caregiver + child (if child answers questions)	Child and likely caregiver (depends)	Caregiver: Standard information and consent sheet (filled in as a caregiver) Child: Simplified information sheet; assent form
<i>Adult with a disability, no or mild difficulty understanding or communicating (with supports)</i>	Person with a disability only	Person with a disability alone*	Standard information and consent sheet
<i>Adult with a disability, moderate understanding or communicating (with supports) but can still answer some questions</i>	Person with a disability AND caregiver	Person with a disability and caregiver	Caregiver: Standard information and consent sheet Person with a disability: Simplified information sheet; assent form
<i>Adult with a disability, very severe difficulty understanding or communicating (with</i>	Caregiver	Caregiver alone*	Standard information and consent sheet (filled in as a caregiver)

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<i>supports), cannot answer any interview questions</i>			
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\*Alone unless another person is specifically requested by the interviewee or required for communication (e.g. sign language interpreter)

### 4.3. How to take consent

#### Phone interviews

Read the "Information Sheet" (simplified or standard) to the participant or confirm with them that they have read it if you have sent it to them previously. Once you have finished reading the information sheet, check if the participant has any questions. After you finish answering all their questions, explain that you must record their consent their to participate.

You can say: "If you are happy to proceed with the interview, I will need to record that you have agreed to this interview and that you understand the study procedures. I will now turn on my audio recorder and ask you to confirm a few statements." If the participant agrees:

- Turn the audio recorder ON
- Read the 5 bullet points on the "Informed consent form" or "Assent form" (children or adults with difficulties understanding/communicating with available supports)
- Say out loud: "Today is [DATE]. If you agree to participate please state your full name now."
- Once they have said their full name out loud, STOP the audio recording
- Save the audio recording using their ID number (column 2 in the table above)

Please note, the consent should be a SEPARATE recording from the full interview.

For interviews conducted with sign language, you can record the video of the participant signing their name.

#### In-person interviews

Read or ask the participant to read the "Information Sheet" (simplified or standard). Once you/they have finished reading the information sheet, check if the participant has any questions. After you finish answering all their questions, provide them with the "Informed consent form" or "Assent form" (for minors/adults with difficulties understanding/communicating). Ask them to read the 5 bullet points (or read them out to the participant if they cannot read). If they are happy to proceed, they must sign and date the form.

## 5. Confidentiality

One of the biggest responsibilities of data collectors is to keep the information that participants share CONFIDENTIAL. Participants are trusting us with personal information and we have promised them in the consent process that we will keep this information private.

There are several steps that need to be taken to ensure we are keeping information confidential.

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1. Do not share/discuss information on any specific individual with anyone outside of the research team. **Remember, people can be identified even if you don't use their names.**
2. If you are conducting separate child and caregiver interviews, do not share information between the participants (e.g. do not share what the child has discussed with their parent/caregiver). If the child discloses information which is a child protection concern (i.e. violence, self-harm) immediately contact the study lead.
3. Keep discussions within the research team limited to what is necessary for the study.
4. Do not share audio recordings, notes, filled in consent forms with anyone outside of research team
5. Keep the audio recorder, recording files, your notes and consent forms safe. Do not leave them unattended. If stored on a computer, make sure your computer/the files are password protected.
6. Destroy all the study materials as soon as you are directed to by the research team leads.

### 6. General Interviewing Technique

When conducting interviews, there are several key points to keep in mind:

- **The topic guides are just a starting point** – You should cover all the questions listed. But you **MUST** ask additional follow-up questions. Treat the interview as a discussion. If someone says something interesting/important/incomplete/unclear, ask for more details. You can also ask the questions in a different order/phrasing than written on the guide.
- **Do not suggest answers to the respondent** – this can lead to inaccurate data
  - e.g. Say things like: *“How did you feel at this point?”* not *“Did you feel sad at this point?”*
- **Ask simple questions** – not questions with several parts/ideas
  - e.g. Don't ask *“What did you think of the whole experience: the hospital, the treatment, getting there?”* Break this down into several questions to explore in greater detail.
- **Limit one word answer questions** – this can limit in-depth conversation
  - e.g. Don't ask *“Did you like school?”* but instead *“What did you like about school?”*

Your attitude as the interviewer is also very important to ensuring we collect good quality data. Some points to keep in mind include:

- **Be motivated, engaged with respondent:** make the interview feel like a friendly discussion, rather than a long, boring chore. Enthusiasm is catching, so if you remain upbeat and engaged, it's more likely the respondent will be too.
- **Be neutral:** careful of body language, attitude, tone of voice and how this might influence respondent
- **Be respectful, patient:** never scold a respondent or contradict what they are saying. Always remember that participants are giving us their time for free.

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### 6.1. Ask follow up questions

Follow-up questions (also called probes) are used to get a more complete picture of a participant's experience. They can also help ensure that the answers given by a respondent are as accurate and as complete as possible.

**Follow-up questions are not written down on the interview guide, so you will have to add them yourself.** The decision to ask follow-up questions depends on your judgment and what is said during the interview. You should use follow-up questions to:

- Gather additional information on anything you think is relevant to the study
- Encourage respondent to express him/herself fully
- Help respondent better understand question
- Clarify unclear/contradictory responses

When in doubt, always ask follow-up questions. It is much better for us to have some information that we don't need than to be missing important information that could help us better understand the participant's situation.

Whenever you ask follow-up questions, it is important that it is neutral and non-challenging. Importantly, the way it is phrased must not influence the participant (i.e. suggesting a particular answer).

DO's	DON'Ts
"Can you tell me more about that?" "What happened next?" "How did you feel when XX happened?"	Only ask questions that are on the interview guide
"What do you mean?"	"Do you mean XXXX?"
"Please explain that"	"Are you sure it's not XXXX?"
"I'm sorry, but a few minutes ago I thought you said [CONTRADICTIONARY INFORMATION]. Could you clarify this for me?"	"You said before [CONTRADICTIONARY INFORMATION]. So what you just said now can't be right. I think you mean XXX"
"I'm not quite sure I understand what you mean by that. Could you tell me a little more?"	"You're not making any sense."

## 7. A few notes on working with people with disabilities

### 7.1. General considerations

People with disabilities want to be treated in the same way as people who do not have disabilities. As with everyone, always relate to the people with: respect, dignity, empathy and equality. Do not assume that a person with a disability requires special treatment all the time.

Still, you may need to adapt your interviewing approach to ensure people with disabilities are better able to participate.

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Some general guidance to follow:

- Always **talk to the person with a disability to decide if they will be able to participate in the interview**. Do NOT rely only on what the caregiver tells you. Often, people underestimate the abilities of people with disabilities. Even if their contribution is limited, any direct input is valuable.
- When you call to set a time for the interview, ask the person (or caregiver) about **what adaptations might help the person to participate more fully**. See 7.2 for some impairment specific ideas.
- **Always value the contributions of the person with a disability**. In rare cases where a caregiver is present during an interview, the contribution of the person with a disability is the priority. Always take their responses above that of their caregiver, unless you truly believe the person has not understood you (after repeated attempts).
- **Always talk TO the person with the disability** if they are in the interview. Not their assistant, interpreter or anyone else.

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### 7.2. Considerations for people with different impairments

Area of difficulty	General notes	Adaptations for consent	Adaptations for interview
Seeing	<ul style="list-style-type: none"> <li>• When you approach the person, identify yourself clearly/tell them who else is present</li> <li>• Tell them when you are leaving so they aren't left talking to an empty space</li> </ul>	<p><i>Written</i> For signing, if the person cannot read the paper, they can give an oral consent/thumbprint. THIS MUST BE WITNESSED by another person, who then signs (in the proxy space)</p> <p><i>Oral</i> No adaptations needed</p>	None needed. If this is their only area of difficulty, ask the questionnaire as usual.
Hearing	<p>Ask what adaptations might help the person participate more fully. This can include:</p> <ul style="list-style-type: none"> <li>• Talking louder/being in a quiet room</li> <li>• Reading/writing instead of answering verbally</li> <li>• Using sign language: if a person uses a standard version of sign language (i.e. not an informal, home-based system), we can get a sign language interpreter</li> </ul>	<p>Adapt consent based on what the person is or is not able to do (e.g. if they can read, get them the information sheet to read; if they use sign language, have it interpreted).</p> <p>Only use a proxy if they are deaf, don't know standard sign language and cannot read.</p>	<p>If the person can hear a bit, sit in a quiet room and speak slowly at a louder volume (but don't shout at the person).</p> <p>If the person uses sign language, contact SRC about organizing an interpreter visit. For phone interviews, you should use a video conferencing app (e.g. Zoom, Skype).</p> <p>If the person can read, have them read the questions and write responses.</p>
Physical (mobility, use of hands, lifting)	<ul style="list-style-type: none"> <li>• Wheelchairs, assistive devices are part of their personal space – do not touch or move without asking</li> </ul>	If person has difficulties using their hands, they may need to give a thumbprint instead of a signature.	None needed. If this is their only area of difficulty, ask the questionnaire as usual.

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	<ul style="list-style-type: none"> <li>• Personal assistant's generally do not need to be present during an interview, unless specifically requested by the interviewee</li> <li>• Make sure you conduct the interview somewhere accessible</li> </ul>		
Intellectual (understanding, remembering)	<ul style="list-style-type: none"> <li>• Always check for yourself how well the person understands. Don't rely on other household member's information alone – try asking a few general questions to gauge their understanding (e.g. What's your name? How are you today?)</li> </ul>	<p>You may need to spend more time on the consent, breaking down difficult concepts. Be patient and allow time for questions</p> <p>If you are unsure a non-minor fully understands, you can also have a caregiver sign.</p>	<p>Be patient and give positive reinforcement, but don't put 'words into their mouths'. Allow time for the person to answer.</p> <p>You may need to adapt the questions by using simpler language.</p> <p>If someone is assisting you with communication, try to get as much information from the person with a disability themselves.</p>
Communication (difficulty speaking)	<ul style="list-style-type: none"> <li>• Find out the preferred communication method of that person. It may be that they understand but have difficulty speaking; or they may also have understanding issues as well.</li> <li>• Don't speak for the person. Wait until they finish and resist the temptation to finish sentences for them.</li> <li>• Never interrupt or correct a child who has a communication impairment.</li> </ul>	<ul style="list-style-type: none"> <li>• If they also have difficulty understanding, see above.</li> <li>• If only with communication, ensure they've understood key points.</li> </ul>	<ul style="list-style-type: none"> <li>• Some possible adaptations:             <ul style="list-style-type: none"> <li>○ Substitute nods/gestures for verbal responses (you may need to ask more yes/no questions)</li> <li>○ Ask caregiver/child how they usually communicate with family, friends</li> </ul> </li> <li>• If you do not understand, do not pretend that you do. Repeat as much as you did understand and use their reactions to guide you. Ask them to tell you again, if necessary</li> </ul>

## 8. Frequently Asked Questions

1. *A household member says the person with a disability won't be able to understand me. What should I do next?*

Ask to speak to the person with a disability yourself first.

Ask the person with a disability some simple questions (e.g. "What's your name", "How old are you", "How do you feel today"). If the person can respond, you should continue with an interview. You may need to make some adaptations to the interview (see section 7.2).

You should also ask the person with a disability or the other household members ways to help with communication. For example, ask other household members how they typically communicate with the person with a disability.

If you feel that the person with a disability does not understand you at all, even after trying all available adaptations, only then can you use a proxy.

2. *People keep coming by while I'm conducting an interview. I don't think the participant minds and I feel bad asking them to leave. Can they stay?*

It is important to maintain privacy. Participants might not feel comfortable sharing information with others present. Even if asked, they may feel pressure to say they are ok with others being present.

As the interviewer, you must enforce privacy. Ask the participant to pick a space that is quiet, where they are comfortable and where you can speak without being overheard. Before the interview, once alone with the participant, say "We usually do these interviews with just the two of us. However, if you would prefer someone else to join – for example, if this would make you feel more comfortable - please let us know." Only allow others to join if specifically requested (and even then, only the requested individual). Do not ask the participant again, for example, when someone comes by and wants to join.

If other people come by, you can briefly and broadly explain what the research is about (e.g. we are doing research on disability). You can then say that you must follow the study protocols and are unable to continue if other people are present. Stop speaking if they don't leave, which will usually encourage them to move away.

It is fine if small children are present, if they cannot understand/repeat what is said in the interview. Interpreters and others helping with communication are also fine (but only as needed/requested).

3. *The phone/video connection drops mid-way through an interview. What should I do?*

At the start of the interview, it's good to discuss backups for what to do if the connection fails. For example, is there an alternative number you can call the participant on? If the call drops, pause the recording and try to calling them back. If you can't reach them, you may need to reschedule the remainder of the interview for another day/time.