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Guide to Qualitative Research on Patient Perspective on Medicines Use

The WHO Collaborating Center for Research and Training in the Patient Perspective on Medicines Use

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UNIVERSITY OF COPENHAGEN
DEPARTMENT OF PHARMACY

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Introduction

In order to promote rational use of medicines in society, we as policy makers, regulators, health care professionals and researchers need to know more about the perspective of medicine users/patients including what patients' motives and rationales are behind their medicine intake, and what ideas, experiences, perceptions, attitudes, etc. are built into these rationales.

Qualitative methods can be a way to gain this understanding. You will often find that patients make very rational decisions about their medicines, but make them according to other rationalities and prioritizations than those of the professionals. Therefore, using qualitative research techniques in the attempt to promote safe and rational drug use, including finding ways to involve patients in medical decisions, is an efficient way to align the knowledge and experience of the professional world with the life world of patients.

This Guide introduces different important aspects about how to prepare for qualitative interviews – from initial thoughts to dissemination. The aspects are presented according to our experiences gained by using these same methods over many years. The different presented chapters can be read in a consecutive order or independently.

If you are in need of further advice on how to do qualitative research on patient perspective on medicines use, please contact us to inquire about existing plans of specific training seminars or the possibility to obtain individual supervision for upcoming or ongoing qualitative research studies. We possess similar knowledge about focus group interviews, qualitative observations and document analysis.

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When and why to use qualitative interviews

Most often, qualitative studies are concerned with answering questions such as "*what is X and how does X vary in different circumstances, and why do X vary?*" [1]. Therefore, qualitative studies typically answer questions like "*how*?" and "*why*?" [2] – and the same goes of course for qualitative interviews. The qualitative interview method is used to explore meanings, perceptions, attitudes, experiences, thoughts, feelings, knowledge and behaviors in order to get a deeper understanding of a phenomenon, and more precisely the phenomenon seen from the point of view of the interviewees [1-2].

This is in contrast to quantitative methods such as surveys or questionnaires, which are more appropriately used for measuring and quantifying the research field, and which are very much concerned with "*how many Xs are there*?" [1]. Examples of research questions that might be answered using qualitative interviews could be for instance: "*How do patients cope with their chronic diseases*?" or "*What characterizes the cooperation between hospital pharmacists and community pharmacists*?".

Qualitative interviews result in a lot of information, often in a rather unstructured format. This enables the creation of new understandings and new meanings, but also requires a lot of resources, not least time and money. Hence, the time you should spend on a qualitative study not only includes carrying out the interviews, but also analysing data, transcribing the interviews and possibly writing up a report or an article to disseminate the results. Stating the exact time needed to complete a qualitative research is difficult. However, a thorough qualitative study including 15-20 interviewees would take around 3-4 months to complete [3].

Having said that, a great advantage with qualitative interviews is the built-in flexibility which makes it possible to follow up, go more in-depth and explore what is behind the speech – which can make us see the world from a new point of view, as it is expressed by affected people in their own words [1-2].

Different types of interviews

Each interview type has its advantages and its disadvantages. The type you select depends on your research design, that is to say on what kind of insight you want to get out of your interviews.

You can choose between unstructured, semi-structured or structured interviews.

Unstructured interviews

Also called narrative interviews, unstructured interviews are carried out with few, if any, interview questions. These interviews often progress like a normal conversation; however, it concerns the research topic under review. Unstructured interviews are helpful when dealing with sensitive topics, and when you need to get an in-depth understanding of how that person, for example a patient, understands and deals with their medicine. If you select this interview style, you might want to conduct several rounds of interviews with the same interviewed person in order to get a deeper understanding of their experiences.

Semi-structured interviews

Semi-structured interviews are the most frequent type of interviews. Before a semi-structured interview is carried out, an interview protocol is developed to help guide you through the interview. Semi-structured interviews maintain some structure through following the interview guide (hence the name semi-structured), but they also provide you with the ability to probe for additional details, thereby steering away from your interview guide, offering a great deal of flexibility. You would therefore usually choose semi-structured interviews when you really want to understand the perspective of the interviewee while allowing space for further additional questions.

Structured interviews

Structured interviews are interviews that strictly adhere to the use of an interview protocol. It is a rigid interview style, in that only the questions on the interview protocol are asked. As a result, there are not many opportunities to probe and further explore topics that interviewees bring up when answering the interview questions. This method can be advantageous when researchers have a comprehensive list of interview questions, as it helps target the specific phenomenon or experience that the researcher is investigating [4].

You then have to choose the modality of the interview: face-to-face interviews, online interviews via Skype, messaging, or video, and telephone interviews.

Telephone interviews can seem efficient, but you would lack visual cues, leaving you as a researcher with loss of contextual and nonverbal data. We recommend to avoid them if possible.

Online interviews have both advantages and disadvantages compared to face-to-face interviews. They enable you to carry out interviews with a very geographically dispersed population, interview individuals or groups who are often difficult to reach (physically mobile or socially isolated persons, etc.) and conduct interviews in a personal, yet neutral, location such as a home.

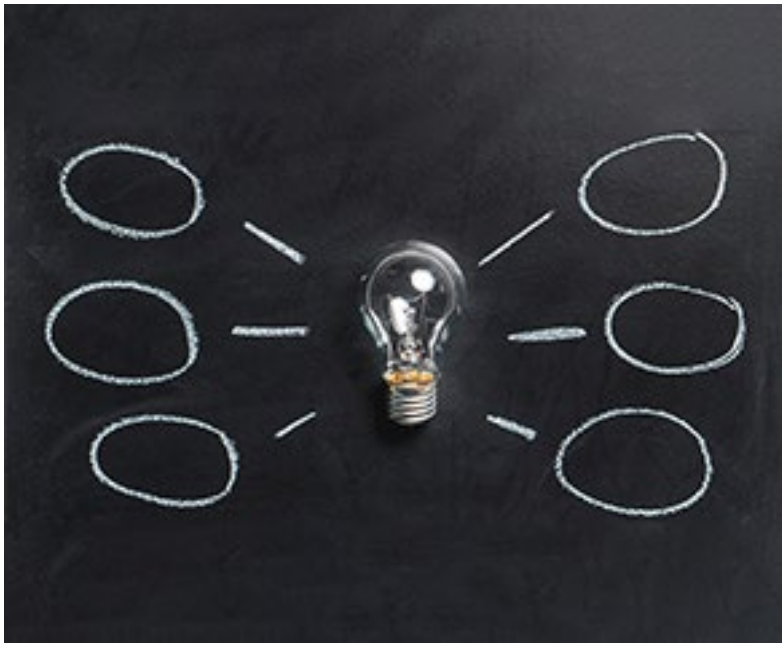
Disadvantages related to online interviews include the difficulty to establish a good level of trust between you and the interviewee in a computer-mediated research relationship, the risk of technical problems and maintaining attention, since you do not control (or are even aware of) distractions that are interrupting the interviewee's engagement with the interview [5].

Aim of interview and research question

All research starts with a question, i.e. a quest for learning something new: for example, about the medical knowledge, beliefs or practices of patients. This quest can be formed by the wish of understanding the reasons behind a specific health or health-care related problem. A project purpose could also be to document existing practices, for example, to specify the practices and develop them further. For some examples, see references [6], [7] and [8].

The overall research question may be divided into several sub-questions that should all be answered. Make sure that your research question is clear, hence, that you know exactly what it stands for, otherwise, it will be difficult to make an interview guide that will help you answer it. If it is difficult to specify the question by the beginning of the project, you may specify it a bit later in the project when you get to know the area better [9-10].

Make sure that you do not repeat research that has already been done, by investigating the existing literature in the area. Getting familiar with the existing literature also makes it possible to specify your own research question. Therefore, you might realize that there is a particular part of a problem that you want to investigate more in depth. Only after defining the overall research question of the project, can you decide which method to use. Therefore, always decide the research question before deciding the method. If the aim of the project is to understand perceptions, feelings and/ or experiences of a particular group of people, a qualitative interview is an adequate method [1].



Ethics

As with all research studies involving people, ethics is an important factor when conducting an interview-study. One ethical aspect, which is very general, is *what are the consequences of the study itself, and what can it potentially improve*?

Another aspect is if there might be any possible harm done to interviewees. Interviews can have an effect on the interviewee that you cannot foresee, both positively and negatively. It could be, for example, that the interview is about an experience the interviewee has not put words on before, and therefore makes them become more aware of certain issues that makes them take new actions; or it could bring up memories that are unsettling. Therefore, special attention should be paid when conducting research in sensitive topics and/or among vulnerable population. The risk of harm should be reduced as much as possible, or the interviewee should at least be aware of it when consenting to be interviewed. We cannot know what individual persons react to, but information beforehand gives them the opportunity to reflect on this before they agree [4].

Ethics, as in a power relationship or responsibility between interviewer and interviewee, also have to be considered. Interviews can be said to be a unique form of conversation, where thoughts and perspectives are exchanged through dialogue. However, the balance of power between interviewer and interviewees is asymmetric, as the interaction is not mutual between two equal parties. The interviewer defines the situation, introduces the conversation topics and asks the questions. Therefore, it is important to indicate in your interview study how ethical considerations will be addressed [11]. Ethical considerations could be any of the issues discussed in this Guide.

If you plan on conducting research within the European Union, please be aware of the GDPR rules of 2018 with regard to protection of data containing information about individuals and other required national legislation concerning ethical reviews and approvals. If you work outside of the EU, please also be aware of and comply with national laws. These approvals must be in place before you start collecting data [4].

Confidentiality/anonymity

Confidentiality, i.e. to protect the interviewees' integrity and identity, should be considered throughout the study. Those who will not need to identify the interviewees should not be made able to do so, and the interviewees should be made aware of who will know about their identity, e.g. members of the research groups. Make sure, in all phases of the product, that the interviewees are anonymous. This does not only include not sharing their names, but also not sharing information that could potentially identify them (e.g. age, sex, religion, work place, diagnosis, interests, home town in combination). Make sure that data - from contact information to transcripts - is stored in a secure way (see above). This is relevant regardless of whether the data is on audio recorder, paper, electronic or some other media [4], [11].

Informed consent

Informed consent can be oral or written. It is important that the potential interviewee understands enough about the study and their participation in it to produce an informed consent. Therefore, make sure that enough information is given about the study, its consequences and other potential consequences for the interviewee. The interviewee should also be informed about the possibility to withdraw from the study, also once the interview is performed (however, withdrawing after the publication of the article is impossible - but until then). Examples of informed consent forms can be found in the Free Management Library.

It is beneficial to provide both written and oral information – and there should be an opportunity for the interviewee to ask questions about the study and their participation in it. Make sure the interviewee gets some time to think about participating before giving consent, they should not feel pressured. You should also make sure that the interviewee has understood the information, e.g. by asking them to repeat some of it [10].

If the interviewee is a child or a young person, informed consent should usually be given by both the interviewee themselves and from a parent or another relevant person.

The interview guide

To make sure the interviewee provides you with answers that will enable you to answer your own research question(s), you should prepare an interview guide. An interview guide might be unstructured, semi-structured or structured according to what type of interview you are carrying out (read more p. 5).

Unstructured interviews

An unstructured interview guide consists in perhaps just one to two questions, and then about letting the interviewee talk, without the interviewer interrupting them. Instead, the role of an interviewer is to encourage them to tell more about themselves and their experiences with a certain topic. The interviewer might also ask probing questions, that is to say to ask the interviewee to explain more aspects around some of the issues they mention.

Semi-structured interviews

Interviews are most often semi-structured. This type of interview guide should be balanced in a way that enables the interviewer to address specific issues in relation to the research question, but still allowing the interviewee to show their true opinions, perceptions and experiences. One way to create this balance is to create themes in the interview guide. Each theme can then consist of several questions. Very often, the interviewee stirs away from the interview guide – for example, they jump the order of questions, start going into depth with a particular question, or start discussing something not relevant to the project. If this happens, you should try to get back on track politely. It is considered that the best interviews are those that develop in another order that planned, as the interviewee has better chances of showing their personalities and thereby their true perceptions [10], [13], [14]. It is important to feel that you have covered all the themes when you have finished with the interview. It is not necessary to have answered meticulously to

all questions under each theme. Keeping track of the themes rather than individual questions will allow optimal flexibility, thereby enabling the interviewee to better show their personality. Building your interview guide in themes will also help you keep an overview of those you have covered and of those that should still be dealt with [13].

Structured interviews

The interview guide might also be structured. Specific questions are included in the interview guide, and questions are asked following a specific schedule. If the interview guide is highly structured, it would often be considered a quantitative, rather than a qualitative research method, as it might not allow the interviewed person to show their true character.

You will need structure, even with an unstructured and semi-structured interview [9].

It is preferable that you explain the purpose of the project and the proceeding of the interview in the beginning. Make sure that the interviewee gives their informed consent for the interview if this has not been done earlier – see also Ethics and Preparations before interview.

You then start the interview by asking some basic questions, that are easy to answer. You thereby warm up the interviewee slowly, to make them relax, preparing them to answer your questions. This will help you get a good understanding of who the interviewee is, and will enable the interviewee to start reflecting and expressing themselves. These warm-up questions could be about their daily lives, or their conditions, or their diagnose. You can then ask questions related to the themes in the interview guide.

At the end of interview, make sure the interviewee still feels comfortable with participating in the project. You may also try to sum up areas in which you are a bit uncertain, to help the interviewee correct you. This can also be done while the interview is proceeding [10].

An interview guide could be revised from interview to interview (at least the unstructured and semi-structured ones). If you realize after a few interviews that a theme is missing, i.e. if you found a new important theme that you did not consider from the beginning, you should add it to the interview guide. You make therefore sure that the answers from interviewees are always as relevant as possible, in order to answer the research question of the project. It is better to have a few answers to a question, than no answers at all [10].

Sampling

As the goal of qualitative research such as interviews is to provide in-depth understanding of the thoughts and behavior of a selected group of patients, it targets a specific and smaller group (or type of event or process). Therefore, you will typically not need a large sample, but a small one consisting of the right interviewees, who possess the characteristics you have set up prior to running your interviews.

To accomplish this goal, qualitative research focuses on *criterion-based sampling* techniques (also entitled *information-oriented sampling*) to reach, recruit and include the right target group. In practice, this means that you first reflect on which kind of interviewees you want to include in your study, then are able to argue for this choice, and finally ask such people if they are interested in participating in the study. There are different types of qualitative sampling techniques. Only the two most common techniques are mentioned below, namely *purposeful sampling* and *snowball sampling*. For other sampling strategies and examples, see reference [9].

Purposeful sampling

It is the most common sampling strategy, and thus recommendable for most interview studies. Interviewees are selected or sought after based on pre-selected criteria/characteristics (for instance age, sex, marital status, socio-economic status, education, occupation, health status, religion, etc.) based on their relevance for the research question. The sample size (typically much smaller than in quantitative research) may be predetermined according to available resources or based on theoretical saturation (which is the point at which the newly collected data no longer provides additional insights). This means that you cannot determine the number of interviewees from the beginning of your study, but have to analyze the data little by little and at the same time as conducting the interviews, in order to assess when saturation has been achieved.

Snowball sampling

In *snowball sampling* a (potential) interviewee can often refer you as an interviewer to others who may also have the right attributes to participate in the study. This method will help you to find and recruit interviewees that may otherwise be hard to reach.

Preparations before the interview

Once you have obtained the interviewees' acceptance to participate in the research project, the interview has to be prepared.

Develop written and oral information about the purpose of the study, and about how the interview of a person is going to be used in relation to the purpose of the project. The written information should include contact information of the investigators, so that interviewees can contact them, if they want to leave the project or obtain more information. The written information can also be handed out when recruiting.

The location should be left for the interviewee to decide. It could be the interviewee's workplace, the investigators' home or office, or a neutral place like a café. The interviewee must feel comfortable with the location, and there must not be too many distractions. As interviews should preferably be audio-recorded, it is also important that the place is quiet, as it can otherwise be difficult to hear on the recording what will be said. Make sure that the audio-recorder, which could be a smartphone app, works as intended before the interview. Bring an extra recording device just in case.

The interview guide should be well known and rehearsed by the investigator before the interview. Make sure you are completely familiar with the themes and purposes of each question, so even though the interview develops in an unforeseen way, you are sure to be able to get back to the questions you aimed at. Being more than one interviewer can be an advantage, as you can help each other and keep track of what has been asked or not; be sure to have discussed what roles each interviewer has before the interview starts.

The interview situation

The interview is not a "normal" conversation; it is about a researcher who wants to obtain information from an interviewee. In the interview situation, the interviewer needs to do many things in parallel: listen, prepare the next question, consider follow-up questions, be aware of what is happening with the interviewee (e.g. body language), keep the time, and be aware of how much of the interview guide is left. In short: think in advance while at same time be very attentive and present [13]. Interviewing is a difficult discipline, so it is recommended to rehearse and practice in order to become a good interviewer.

Before starting the actual interview, you should be sure that the informed consent is in order (please also see Ethics). Inform the interviewee about the purpose of the interview (even if that has already been done in advance) and what will happen after the interview, e.g. how it is going to be reported [10]. There are some aspects you need to consider when interviewing in order to get as deep and nuanced answers as possible [13], [10].

- Be aware of any differences between you and the interviewee. You might come from different social, cultural, ethnic or educational backgrounds. Make sure the interviewee feels that you accept and respect them and what they have to say.
- As an interviewer, you need to show empathy and understanding. Explain that are no "right" answers. This includes being aware of your own behavior, e.g. body language, voice and

facial expression. You should encourage the interviewee to share their thoughts, experiences, knowledge etc.

- Leave your preconceptions behind, and avoid leading questions. Be aware of social desirability, which is when people may want to please you by saying what they think is the right thing to say, rather than what they really mean. Avoid this by being genuinely curious, open-minded, encouraging and non-threatening.
- It is your responsibility to establish a safe and comfortable environment for the interviewee during the interview. This is because you want the interviewee to be open, willing to share thoughts and ideas and to speak freely.
- Listening is a crucial part of the interview situation, and you should listen more than you speak. Make space for the interviewee to reflect about their answers. It can take time for people to find the right words - silence can be a revealing experience - so do not rush. Pauses are not embarrassing at all. In fact, pauses give the interviewee a chance to reflect, think and relax.
- Use follow-up questions and probing, signaling that you want the interviewee tell more, go further in what they are saying, e.g. by asking “could you say more about this?” or nodding and repeating a central word the interviewee just said.
- If you are in doubt about what the interviewee meant with a certain statement, feel free to ask them to rephrase the answer. Also ask (even if you do not feel it is necessary) if you have understood the interviewee correctly, to make sure that you are not misinterpreting their thoughts.

Transcription

Transcribing an interview, i.e. transforming the audio-recording of the interview into a transcript, is important in order to be able to conduct analysis. The transcription process is rather time-consuming, but can serve as a first step in an analysis, regaining familiarity with the interview, its atmosphere, what was said and how.

Transcribing an interview into a written text is obviously a reduction of the different types of impressions you might get in an interview situation. However, unless you know how to work analytically with other elements than the spoken word, such as the length of breaks in speech, facial expressions etc., transcribing the interview verbatim (and thereby not transcribing other elements than the spoken word) is adequate. However, expressions like laughs should also be noted in the transcription, when they are relevant for understanding the true meaning of what was said, for example if the person said something ironically.

Depending on the aim of you study, and your method of analysis, you may leave out parts of the interview from the transcription, e.g. if the interviewee started talking about something that is not relevant to your study.

Make sure when transcribing that all personal information is deleted or changed into 'codes' (such as pseudonyms) in order to protect the anonymity of the interviewee.

Analysis and interpretation

If doing an adequate qualitative analysis of an interview, having a transcription of the interview ready at hand is very helpful [11].

There are two different types of qualitative analyses: content-oriented and theoretical [15-16]. The content-oriented approach regards two overall types of analysis:

1. summarising the main points expressed by interviewees and identifying overlaps in how they experience certain issues, or
2. identifying patterns beyond what is expressed by the interviewees, going more into depth in order to understand why they experience the situation the way they do [15-16]

The theoretical analysis involves using a theory, i.e. that you relate what the interviewee has said by interpreting their statements according to a specific theory. All types of theories or theoretical reflections pertaining in some way to health behavior could be used. A few examples are: the compliance model of Pound et al. [11], the Theory of Planned Behavior [14], or the concepts of "system" and "life-world rationality", as originally described by Habermas [15].

The theory can be chosen before the interviews take place, and should then be incorporated in the interview-guide to make sure that all relevant themes from the theory are covered during the interview. You may, however, also choose the theory only after conducting the interviews. You would then read all the transcripts carefully to get an overall idea of what are the important issues according to the interviewees in relation to the research topic/

question, and then select a theory that would help you explore different relevant nuances of the identified important issues more in depth [15-16].

The procedure of all types of analyses starts with reading the transcripts, and then marking the statements that you find important in order to answer the research questions. Here you should be open for issues you have not reflected upon previously. Group the citations by giving each of them a "code", i.e. a theme. This code can be defined before doing the analysis (a directed analysis) or you may define all of the codes only after reading the transcripts (undirected analysis). It is possible to combine directed and undirected codes. A theoretical analysis is always directed as you interpret according to elements/themes described in the theory/model [15, 16, 17].

When the entire transcript has been coded, you may re-arrange the codes. Some might be merged, or grouped into a hierarchy. All the citations under each code or theme for each interviewee are then compared to get an understanding of what the general content of this code is for this particular interviewee. You can then compare this result with others belonging to other interviewees, to see if they have similar or different perceptions, experiences, etc. to describe the overall patterns. Include another researcher to perform the analysis, or part of the analysis, to ensure validity [15], [17].

Presentation of results

Writing up the results of your interview analysis usually requires some selection of what you deem are the most important outcomes. You would then have many results with different levels and nuances which would be quite overwhelming for a reader to absorb. Therefore, if there are certain results you find of particular importance for the reader to remember, you should focus on these.

Think also about how your different themes from the analysis might relate to each other. For example, instead of presenting ten short different themes, you might, if possible, present themes with more nuances and depth. This gives a more coherent picture for the reader. Having said this, be sure not to leave out any important results, and be sure that you are as un-biased as possible when presenting the results.

As part of your analysis, you would often look for similarities or differences between the perceptions and behaviors of the different interviewees. There are different views on whether you should report the number of participants who said determinate elements or not. As you have a limited number of interviewees, and probably a sampling that does not correspond to proportions in the population, it can be argued that numbers do not matter. On the other hand, it can be interesting to mention an element, especially if a majority of interviewees share the same perception. We would recommend not writing exactly how many of the interviewees are involved in a certain issue; it is preferable to write 'the majority', 'almost all', etc. Besides writing the overall tendencies, you might also report if there were certain interesting and relevant exceptions to this pattern.

The results of the analysis should be described in your own words, showing how you see and understand the themes/sub-themes and the different nuances relating to these. For example, you might find that all interviewees occasionally go to the pharmacy to buy antibiotics without a prescription but for different reasons. In this case, the fact that interviewees occasionally buy antibiotics without a prescription should be reported first, followed by the different types of reasons behind this. It is also important to include what are called 'negative cases', that is to say reporting about the interviewees who think or behave differently. Even though most of your results would consist of your own description of the identified patterns, you should insert a few citations from the transcripts illustrating your points. This also serves to prove that your analysis is indeed based on the interview transcripts.

Data quality and saturation

Ensuring high quality of the interview study is of utmost importance for the scientific value of your research. There are different types of criteria for judging the quality of qualitative research and there are often called different names by the qualitative researchers. However, they all take into account the relevance of the different choices you make (e.g. sampling, method of analysis) and the way you handle your study.

Furthermore, you need to describe the criteria when reporting your study, so that the reader has a basis for judging the quality. Read about the different criteria below, that are a combination of different quality criteria described by other researchers, which we find if of high relevance.

Trustworthiness. The make sure your study can be trusted, the results of your study must be transferable to another context, time, patient etc. To be able to decide on transferability, you need to include a detailed and reflexive description of your results and the context in which the results were found.	*Confirmability.* Has the study been directed by researcher bias or personal rationales, or would other researchers get to the same results as you did? Strengthen the confirmability of your results with a thorough description of arguments for methods used, by detailing the process and analysis, and by describing and reflecting on your own pre-understanding of the subject you study.
Credibility. You results must reflect the truth. You must show that your study was conducted in a thorough way, including all stages of the process, the experience of researchers, the type sampling, and the process of analysis. This will add credibility and validity to your results.	*Authenticity.* Your results should raise the consciousness of the reader, empower a group, or create learning, change, or meaning. It also includes giving all your interviewees the same fair treatment.

Another quality criterion that is often asked for is data saturation. Data saturation refers to the point in the interview process when no new important information could possibly be discovered in data analysis, and this should signal to you that data collection may cease, and that no more interviews are needed. Saturation means that you can be reasonably assured that further data collection would yield similar results, and doing more interviews would only serve to confirm the already emerging themes. When writing a report or an article, you often need to describe when and how your interviews have achieved data saturation.

Data saturation depends on quantity, i.e. how many interviewees, but also on richness of the interview (see below). There is no one-size-fits-all when it comes to the number of interviews needed for reaching saturation, but typically 8-18 interviews would do the job. Saturation also has to do with how deep you managed to go in the interviews (richness). Several but superficial interviews will not lead to saturation, as you will not have thoroughly covered your topic.

Data saturation also depends on your sampling. If you choose to interview only people that are likely to have the same attitudes and experiences, you might think that you have saturated your data, while in reality there are other groups that would bring new perspectives into your study.

References and further reading

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Comments

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