



Genetic Support Network of Victoria

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Participating in Qualitative (Interview-Based) Research

What is qualitative research?

Qualitative research is a type of social research where the researchers are interested in exploring issues, perceptions and phenomena. Data may be collected from one-on-one interviews with the participant, either in person or on the telephone, small mediated group discussions ('focus groups'), or written responses to a questionnaire.

The purpose of qualitative research is to gain better understanding of a phenomenon or an experience, from the perspective of the person who has experienced it, in order to describe the experience to others.

Why should I participate?

Individuals who have a genetic condition, or members of their families, may be invited to participate in qualitative research.

Qualitative research may have benefits for the individual who participates as well as the wider community. The purpose of this kind of research is to gain better insight and understanding of all aspects an experience, for example what it is like to live with a genetic condition. A better understanding can lead to better service provision and better support for others with the condition. The research can be shared with healthcare professionals to give them a more comprehensive appreciation of what a genetic condition is like for the individual who is experiencing it. Furthermore, many participants find the research process personally beneficial. Participants may find the opportunity to tell their story therapeutic in several ways. Some participants have considered this form of interview a socially acceptable way to express grief or other emotions, or a way to reflect on and find meaning in their experience. Many also find it rewarding to have their story listened to and considered valuable.

What are the risks?

With any type of research there comes risk. However, like medical research, all good qualitative research will have been approved by a relevant Human Research Ethics Committee to ensure it is safe, appropriate and worthwhile. Details of the ethics approval should be included in your consent form.

During an interview you may be asked to discuss sensitive topics. See the "What if I find it distressing?" section below.

Will anything I say affect my medical care?

Ethically approved research studies will ensure that participation, as well as choosing not to participate, will not have a negative impact on your medical care or your relationship with any relevant healthcare professionals or support groups.

The Ethics Committee will discourage anyone who is involved in your care from being part of the research team. The Committee will also aim to ensure that you are able to exercise your right to opt out of the research at any time, with no consequences to yourself.

Everything that you say during an interview with a researcher will be kept confidential. See the following section.

Will what I say be kept confidential?

It is an ethical requirement that all information collected by kept confidential. This includes replacing your name with a pseudonym, as well as removing any indentifying information from what you have said, for example doctors' names or names of members of your family. The researcher is also required to store all information, for example your personal details, questionnaires, or transcribed interviews, in a secure way.

Anything you tell the researcher will be used only for the purposes of research, and will not be shared with anybody else, except in a de-identified way. The only exception would be where the research team considered there was a serious threat of harm to yourself or others. In this case, the researchers would consult relevant experts in order to address the threat whilst keeping your conversation as confidential as possible.

What if I find it distressing?

Although the researchers should endeavour to minimise any negative impacts on the participant, there is potential for some participants to find it distressing to talk about sensitive subjects, or to relive emotional memories. In order for the research study to be approved by an ethics committee, the research team needs to have considered this potential, and have made arrangements to provide appropriate support. This may be, for example, a counsellor who is separate to the study being on-call for participants to contact should they wish to discuss any psychological distress they have experienced as a result of the research process.

It is important that you consider this potential for unforeseen psychological distress before you agree to participate in a study.

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Sources:

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