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Deciding whether to participate in research: A community resource for Australians who live with a disability

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ABOUT THIS RESOURCE

Research can be beneficial (sometimes greatly so) in areas such as health, medicine, care and support. However, inadvertently or otherwise, sometimes it can also disrespect the agency of people living with a disability and even perpetuate discrimination, exclusion and paternalistic attitudes.

It is therefore important that appropriate processes are in place to ensure that research is meaningful, ethical, and beneficial to research participants living with a disability.

This booklet aims to support potential research participants who live with a disability to:

- Make an informed decision about whether to take part in a research project
- Be empowered throughout the research process.
- Ask questions and speak up about individual needs to ensure researchers respect the rights of participants.
- Make decisions that ensure researchers treat individuals as participants, rather than just as subjects.

Being involved in research is voluntary. This means that you must freely decide for yourself whether you want to take part. Every person who is asked to be involved in research needs to weigh the cost of being involved against the benefit gained. This booklet will help potential research participants to do this.



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DECIDING TO PARTICIPATE IN RESEARCH

Before the research starts

Before deciding whether to take part in research, people should have a good understanding of the following facts:

1. What the research is about?
2. What the expected outcomes are?
3. What is expected of participants?

Contribution

People need to look at whether the research will make their own life, or the lives of other people, better. People should also consider whether they can make a valuable contribution to the research.

DECISION POINT:

- ★ Based on what the researchers are asking me to do, will I be able to make a valuable contribution?

Benefit

When people are considering benefit, they often think about whether they are likely to benefit personally, or whether others might benefit. The ways that individuals can benefit from research are many and varied, but can include:

- Having access to treatment or testing that might not otherwise be available or is too expensive
- Remuneration for time spent being involved in the research
- Increased understanding about how to manage a condition, personal health and/or wellbeing

The ways other people might benefit can include:

- Researchers and medical professionals learn more about how to treat a condition
- Other people might gain options that you wished you had when you were first diagnosed, developed your condition, or moved back into the community.

DECISION POINT:

Can you clearly identify:

- ★ What the benefit of this research is?
- ★ Who benefits from this research?

Ask yourself:

- ★ How important is it to me that I either benefit from this research personally, or that I help others like me to benefit because of this research?

Risk

There are two elements of risk that people need to explore: Safety and Trust. Both are important. People should compare the risk to themselves against their assessment of the benefit. This allows people to make a balanced decision on whether to take part in a research project.

Safety

It is important to consider physical and emotional safety.

Physical safety includes:

- Am I being asked to do things, or have things done to me, that might cause pain or discomfort?
- If the research involves going to meet the researchers somewhere, am I able to safely get to the location? This may include the safety of travelling through extreme heat, cold or other weather.
- If the environment where the research is being conducted is unfamiliar to me, how am I going to know that I will feel safe and be safe in that environment?

Emotional safety includes considering things like:

- Am I being asked to do something or to answer questions that might be sensitive or traumatising for me?
- If necessary, am I comfortable responding in a group situation?
- What has been put into place to ensure that I will feel safe when doing those things or answering those questions?
- Are the measures that have been put into place enough for me?
- Can I ask for additional support? How would I do that?

If you identify that there are some things that might be physically or emotionally unsafe for you, you might still want to participate in the research if it can be made safer for you. Are the researchers able to offer any additional things to make you safe? For example, are you able to take a support person with you? Is there any way that you can negotiate to have your safety needs met by the researcher/research team?

DECISION POINT:

- ★ If I agree to participate in this research, will I be physically and emotionally safe?
- ★ What might I need to have available to me so that I am sure that I will be physically and emotionally safe?

Trust

People who have been involved in research in the past indicate that trust is important to them. There are many ways that they assess trust.

- 1. Trusting organisations:** Many people suggest that when research has been approved by an ethics committee and is being conducted by a reputable organisation (such as a University), then they trust that the research is safe for them. Others have also indicated that when information about an opportunity to become involved in the research is given to them by an organisation they trust (such as support networks), they trust that the research is safe for them.

Helpful Hint/Think About:

- ★ Even if you trust the organisation that has given you information about the research, and even if the research has been approved by an ethics committee, it is important that you ask researchers about any parts of the research you are not sure about.

- 2. Trusting researchers:** It is important that you can trust the researchers to keep you safe during the research process. Some of the ways that people do this include checking with their family members to see what they think about the research; talking to the researchers before being involved in the data collection part of the research; and getting a sense about how knowledgeable the researchers are about the topic they are researching.

Helpful Hint/Think About:

- ★ You might like to talk to the researchers, or you might like to find out more information about them.
- ★ You may like to check whether the researchers who are named on the information you received are the same people you will be meeting with during data collection.

- 3. Talking to researchers:** Researchers are expected to provide their own contact information. This information is generally provided on information sheets that are provided prior to participation in the research. However, some people have said they feel this information is a legal requirement and doesn't seem like an invitation to have a comfortable conversation with researchers. Depending on the research project and the nature of what you are being asked to do, it is important that you feel welcome to contact researchers to discuss the research project.

Helpful Hint/Think About:

- ★ Keep the contact details of researchers somewhere handy, just in case you need them.
- ★ Consider calling the researchers to ask questions about the research. This will help you to decide how approachable the researchers are for you. Most universities have information about their research projects and teams on their websites. Consider doing a 'Google search' on members of the research team so that you can get a sense of who they are and their experiences.

Convenience

All research will be asking something from you. Most people weigh up the convenience/inconvenience of being involved in the research alongside their assessment of the benefit of the research and the risk associated with being involved. Although there might be other elements of convenience, there are three things that are commonly identified: time, comfort and travel.

Time

It is important that you understand how much time researchers are asking you to contribute. This time commitment should be clearly stated on information that researchers give you. Consider whether you are being asked to contribute time on one occasion or on multiple occasions. Also think about whether preparation time is required. It is important that you take note of any discrepancies that might appear. Some examples of these discrepancies might be:

- You are being offered more remuneration than you expected for what you think you are being asked to do.
- The survey that you are being asked to complete shouldn't take the amount of time the researchers are saying.

Helpful Hint/Think About:

- ★ If there is anything about the time commitment that seems odd to you, call the researchers and discuss this with them.

DECISION POINT:

- ★ Do you know exactly what the researchers are asking you to do?
- ★ Does the amount of time they say is required for the research seem reasonable to you?
- ★ Do you have this amount of time available?
- ★ If the research is being conducted over a longer period, do you know how the researchers will contact you?
- ★ Do you know how to contact the researchers if you have questions?

Comfort/Discomfort

Some research will involve doing things that might cause discomfort. It is important that you understand what this means for you in your situation. Discomfort can be physical (you might need to have a procedure that is not comfortable), or emotional (you might be asked some questions that are highly personal in nature e.g. about your beliefs or experiences). The researchers will have likely pointed out what might be uncomfortable for you during the research process. However, they do not know you personally and they might have missed some things that are relevant to you. Prior to beginning the research project, it is ok to ask the researchers questions in relation to how they will support you to manage your discomfort, should it arise during a research session. It is important to note that experiencing discomfort is not always reason enough to decline participating in the research. But that decision is yours to make.

Helpful Hint/Think About:

- ★ How likely is it that I will experience discomfort?
- ★ What is this discomfort likely to be?
- ★ If I experience discomfort or distress during the research, how will I let the researcher know that I want a break or that I want to stop?
- ★ If I need a support person, can I do that? Who will my support person be? How easy will it be for me to get access to my support person (especially if that support person is a health professional)?

DECISION POINT:

- ★ On balance, will the level of discomfort that I expect to experience be greater or lesser than the benefit of being involved in the research?



Travel

Some research requires you to travel to an agreed place to be involved. If this is the case, then it is important that you think about how you are going to get there; how much it will cost if you are using public transport or your own petrol; will the researchers cover travel costs, or off-set costs in another way (e.g. a gift card for taking part); if you are driving, where you need to park when you get there; is the carpark easy to get to; how far the carpark is from where you will meet the researcher; and how you will find the place that you need to get to. If the place is unfamiliar to you, then you might also need to know things like where the bathrooms are; is there wheelchair access; how many steps there are; and what the lighting is like. You can request visual aids such as a map showing the access route, or a photograph of the building/entry point.

Helpful Hint/Think About:

- ★ Have the researchers given me enough information so that I can get to where I need to go without stress?
- ★ Will I need to allocate additional time to get to where I need to be?
- ★ Will I be reimbursed for my time/costs?
- ★ How will that happen? When will that happen?

DECISION POINT:

- ★ Is there something that I need to talk to the researchers about so that I can take part in the research with minimal stress for me?

Anything else?

There may be other things that impact whether any research is convenient for you to participate in. If you identify anything else that is relevant to you, and that you do not have enough information about, then it is important for you to talk to somebody from the research team.

ONCE THE RESEARCH HAS STARTED

Once you have commenced the research, it is important that you feel comfortable and clear about your role. The research team should check that you fully understand what is required of you and let you know that you can withdraw from the study at any time without penalty. They should explain how they are keeping your information and research contributions safe and confidential. If you need more information about the research, you can ask for this at any time.

Helpful Hint/Think About:

- ★ You can withdraw at any time. If you want to withdraw, how do you inform the researcher?
- ★ If I withdraw, what will happen with any data I have already provided? If it is possible, do I want it to be deleted or am I happy for them to use the data collected to that point?

ONCE THE RESEARCH HAS FINISHED

Research can be a lengthy process. There is often an extended period between when you have participated in research and when the outcomes of the research are available. Additionally, some research is kept confidential and cannot be shared. There are two things to think about that might be important to you when you participate in research: My results and the outcomes from the entire research project.

My results

Sometimes the research you participate in might include results that are unique to you. This type of research is generally clinical in nature and might include blood tests or some other type of clinical data. It might be important to you that you know what your results are. If finding out this information is important, then you need to be sure that you can get the information from the researchers before agreeing to participate.

Ask the researcher:

- Who will get my results?
- Are my results confidential?
- Are my results anonymous?
- How might I get the results?
- Is there something I must do to get the results?
- When can I expect to get those results?

Research results

For some people, getting information about the findings from the research is valuable. Some people are just interested to know what the findings are; for others it can be a sign of respect and that their participation is valued by the researchers. Whatever the reason, it is important that you know if, how and when you might receive those results.

Some research is conducted on a commercial-in-confidence arrangement. If this is the case for the research that you are involved in, then it will be unlikely that you will get information about the outcomes of the research.

For all other research, it should be possible for you to find out the outcomes of the research that you have been involved in, even if you have withdrawn from the project.

Ask the researcher:

- When will the results of this research be known?
- Will they be available to me?
- Will they be available to me, even if I have withdrawn from the project?
- How can I get information about the outcomes of this research?
- Will they be available in a simple, brief, easy to understand format?
- Who can I contact to get information about the outcomes of this research?



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