



UNSW
SYDNEY

Doing Research Inclusively

Guidance on Ethical Issues in Co-Production



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About this booklet



This booklet is a summary of Doing Research Inclusively.

It is called Guidance on Ethical Issues in Co-Production.



Research is when we gather information to learn more about a topic.



Researchers at universities can work on research together with lots of different people.



They can work with

- People with disability
- Disability organisations and service providers.

University researchers can also work with



- Support workers



- Family and friends of people with disability



We call these people **co-researchers**.



Co-researchers are people involved in the research who are not academic researchers.



Co-production means doing research together.

It means people with disability are included in the research processes.



This booklet talks about **ethics** issues that can happen during co-production.



Ethics is about doing things in a good way.

Ethics in research



Researchers in Australia need to make sure they think about ethics when they plan their research.



Research teams do an **ethics application** before they start their research.



An **ethics application** has all the information about how the research will be done.



An **ethics committee** checks the application to make sure the research is done in the right way.



An **ethics committee** is a group that decides on research.



Ethics committees and research teams use the **National Statement** to help them.



The **National Statement** is written by the government.



It gives advice for research teams on things like how to support participants in the research.



It also tells ethics committees how to check different types of research.

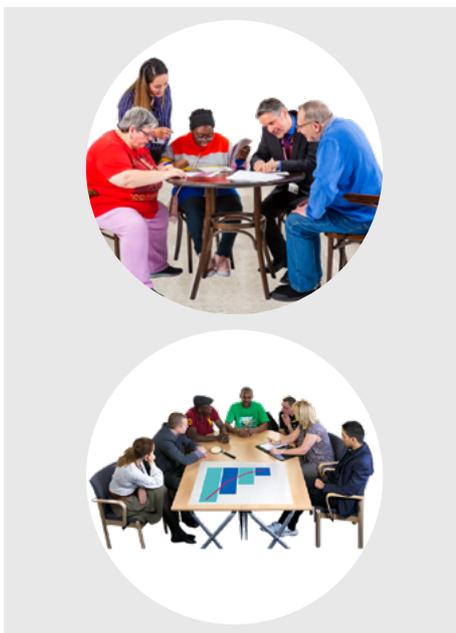
Issues with the National Statement and co-production



The National Statement does not talk about co-production.



It also does not talk about co-researchers doing disability research.



This means there are some ethical issues that have to be worked out by

- Ethics committees
- Research teams with university researchers and co-researchers.

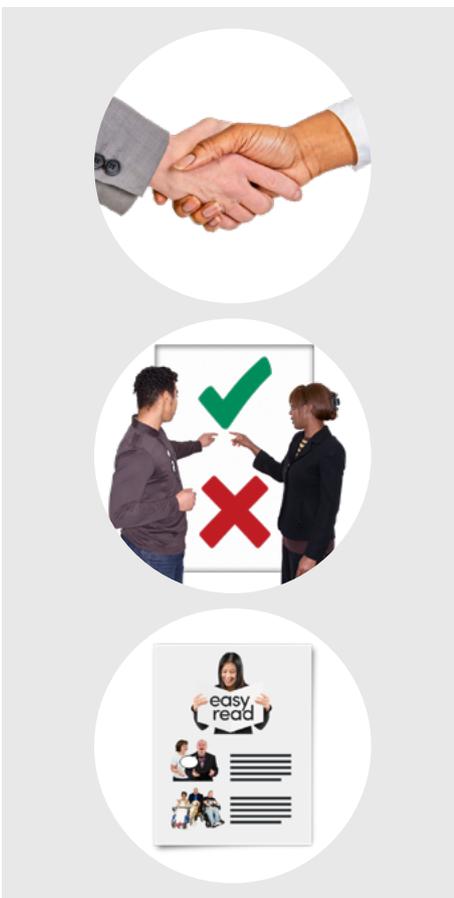


We found there are 6 main issues that ethics committees and research teams need to work out.

Issue 1



Issue 1 is about relationships in co-production.



It is important for the researchers and co-researchers in the research team to

- Work together with respect
- Share decision making
- Make sure that everyone can understand the information.



Ethics committees should check how researchers will work together.

Issue 2



Issue 2 is about how we do co-production in research.



Research teams can find it hard to write about co-production in ethics applications.



This is because things can change as people do co-production in research.



Things like how data will be collected can change.



Research teams should say clearly the ways they do co-production research.



Ethics committees should understand that co-production research is different from other research.

Issue 3



Issue 3 is about roles in co-production.



The different jobs that members of the research team do can have different names.



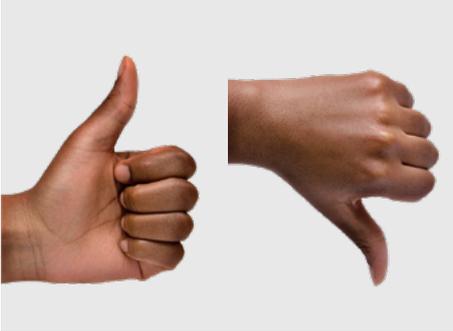
Ethics committees can find it confusing to know each member's role.



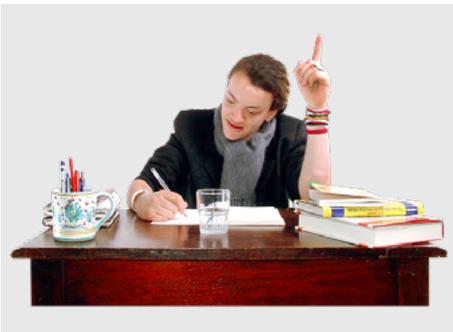
In the ethics application research teams should explain clearly for each member

- The name of their job
- What their job is on the team.

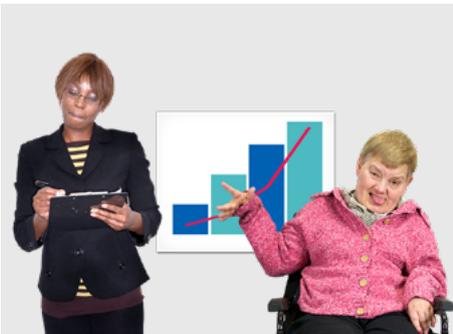
Issue 4



Issue 4 is about **benefit** and **risk** in co-production.



Benefits are good things that can help a person.



This can be like when co-researchers get new skills and training from doing research.



Risks are bad things that can harm a person.



Risks might be co-researchers feeling upset when sharing bad experiences.



Co-production can be safer for everyone when people have worked together before.



Researchers should explain how they will keep the team safe.



Ethics committees should look at both the benefits and risks of doing research.

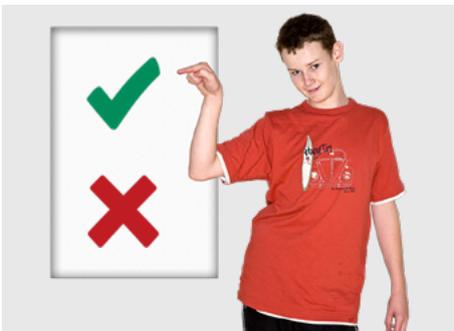
Issue 5



Issue 5 is about **vulnerability** and **capacity** in co-production.



If someone is **vulnerable** it means they can be easily harmed and need to be protected.



If someone has **capacity** it means they are able to make their own decisions.



People often think co-researchers are always vulnerable and do not have skills.



Research teams and ethics committees should use a **strengths-based approach** instead.



A **strengths-based approach** means looking at what everyone in the team is good at.

Issue 6



Issue 6 is about quality in co-production.



Co-production can make research better for everyone.



Right now everyone is still learning the best ways to do co-produced research.



Research teams and ethics committees help us do co-produced research better.



Ethics committees should keep learning about good co-production research.



Research teams and ethics committees should talk to each other.



This helps them understand the best ways to do co-produced research.



This guide was made by the Disability Innovation Institute at UNSW.



Council for Intellectual Disability made this document Easy Read.

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