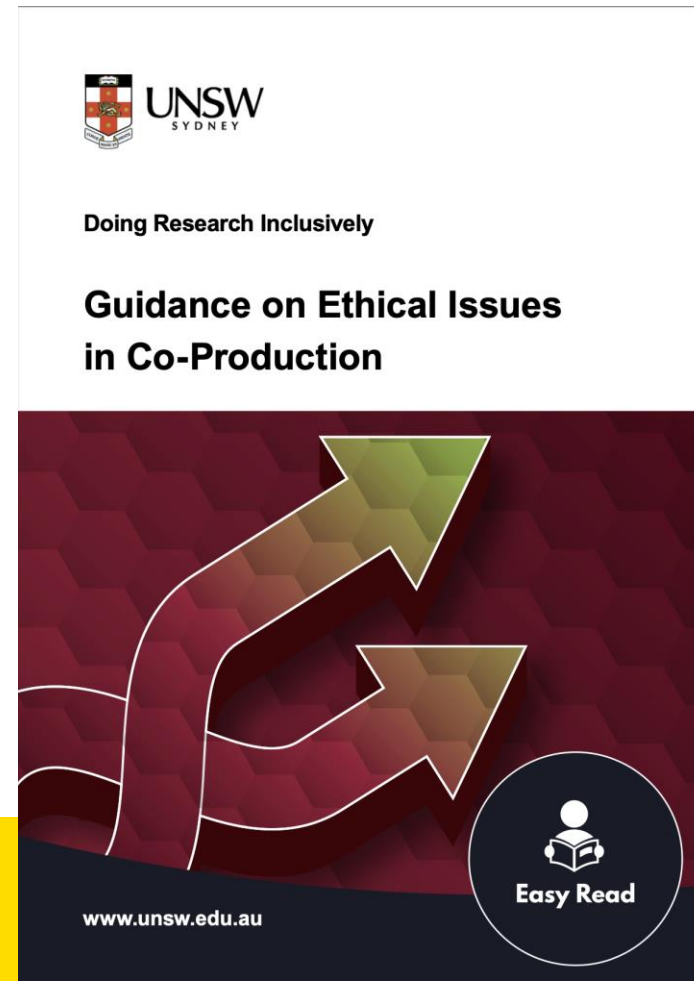


# Doing Research Inclusively: Guidance on Ethical Issues in Co-Production

Professor Iva Strnadová, Professor Emerita Leanne Dowse, and Julie Loblinzk OAM



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We know we are on First Nations land.

We respect the First Nations people from this land.

On this land we

- Live
- Work
- Play
- Swim
- Dream



Berry Island, Wollstonecraft

First Nations people have lived on this land for many years.

Now we live on this land together.

We respect all First Nations people and Elders.

We can learn a lot from their stories.

We can all learn from each other in our lecture today.

This Acknowledgement of Country is written by

- New South Wales Council for Intellectual Disability



Berry Island, Wollstonecraft

# A Note about the Slides



- These slides mainly follow Easy Read principles
- We use many images from [www.photosymbols.com](http://www.photosymbols.com)

**PHOTO**  **SYMBOLS®**

# Acknowledgments – Thank You to



- The National Disability Research Partnership for giving us money to make the Guidance
- Our colleague authors of the Guidance:  
Ben Garcia-Lee, Sarah Hays, Michelle Tso,  
and Jackie Leach Scully
- All the researchers, co-researchers and Chairs of Ethics Committees who spoke to us



# Who Are We?



IVA Strnadová  
UNSW Sydney



LEANNE Dowse  
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JULIE Loblinzk OAM  
UNSW Sydney  
and  
Self-Advocacy Sydney

# Inclusion in Research



- People with disability know their own lives
- Issues important to people with disability
- Contributions people with disability make to research
- Creates information that people with disability can use to (self-)advocate
- Important that people with disability give feedback

# Co-Production with People with Disability

## Co-production

- Is a way to make inclusion happen
- Means doing research together



People with disability are **included** as co-researchers



# Why this Guidance?

- **National Statement**

- Only talks about people with disability with certain diagnoses (cognitive impairment, intellectual disability, mental illness)
- Only talks about people with disability as *research participants*, not as *co-researchers*
- Does not mention co-production

- **Researchers:** have to work out for themselves how to describe co-production
- **Ethics committees:** have to work out for themselves how to check that co-production is done ethically



# How We Made the Guidance



- Looked at what is already written about ethics and co-production
- Looked at what other countries say about ethics and co-production
- Talked to inclusive researchers and research teams
- Talked to the Chairs of Australian university ethics committees

# Important Things We Know about Co-Production



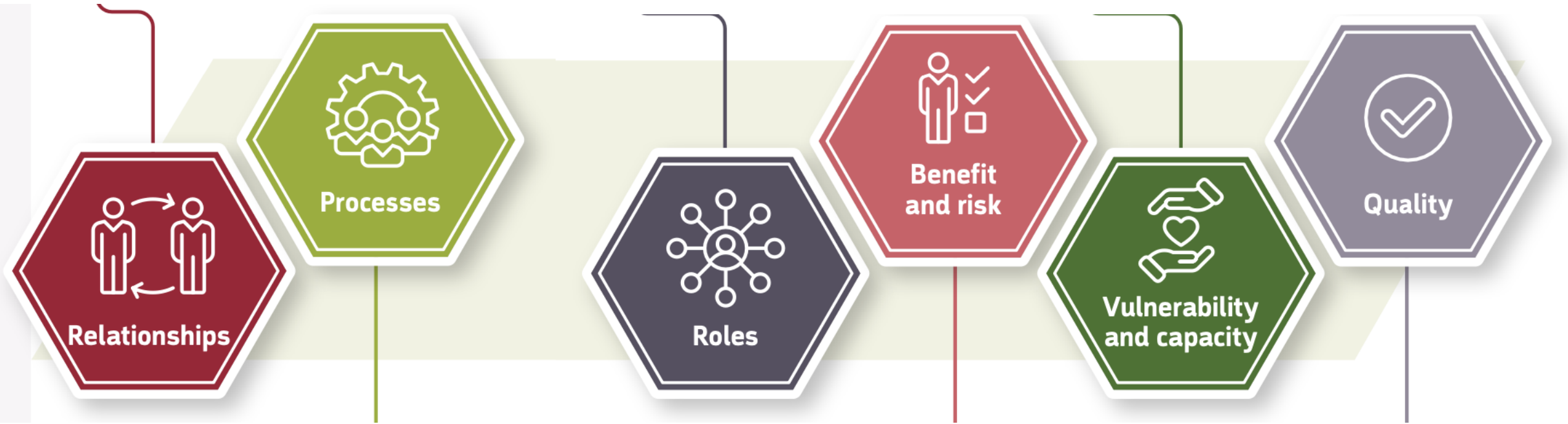
- Co-production can make research better
- Co-researchers can be excluded by the ethics process
- Co-researchers can be hurt by the words used in the ethics process
- Ethics committees might think co-production is too risky for people with disability

# Important Things We Know about Co-Production



- What people think about disability is often connected to what they think about co-production
- Some researchers don't know how to talk about co-production in a way that ethics committees can understand
- Researchers talk about co-production in different ways
- Researchers and ethics committees can learn from each other to make co-production better

# Ethical Issues in Co-production







## ● Strategies for Research Teams

### Model of co-production

- Draw attention to the relational quality of a project by communicating the specific ways in which co-production is implemented within the project, referencing this as appropriate.
- Describe the relationships within the team (past, present, and future) rather than the individual vulnerabilities or capacities of any one team member.

### Safety

- Recognise that all members of the research team may need support at some point.
- Demonstrate how support needs will be continuously assessed.
- Provide support when needed, both in general and in the context of the specific nature and topic of the research.

### Person-centred approach

- Show how respect for and collaboration with co-researchers are demonstrated through all stages of the project.
- Specify how accommodations and accessibility are used throughout the phases of research, and how this may look different from traditional research projects<sup>23</sup>.

### Differentiation

- Clearly distinguish between co-researchers and research participants through explicit definitions.
- Clarify the difference between co-researchers and research participants in practice and how they operate in the specific context of the project.



## ● Strategies for Ethics Committees

### Nature of research relationships

- Ethical co-production should be assessed by examining the nature of the relationships within a research team rather than focusing on an individual co-researcher and their capacity.

### Support

- Consider the potential impact of the research on the well-being of researchers and co-researchers.
- Evaluate the stated measures in place to mitigate or minimise potential harm.
- Assess whether supports have been adequately considered and how they will be implemented, including debriefing, communication support, accessible formats, appropriate training and/or mentoring.

### Specificity

- Provide a section within ethics application documentation to prompt research teams to detail how the project operationalises a co-production relationship.



### Ethics Committee Chair Insight

*“Co-production, for me, has to come out of relationships, and those relationships take an investment of time and energy. It’s got to be based in a relational encounter. Not transactional, but having more invested in it, that you have to give something.”*



## Relationships in Co-Production



- Co-production is a relationship
- Working together, respect, making decision together
- Power-sharing, inclusion and accessibility, person-centred approach to collaboration

### **Ethical co-production is**

- About the relationships within a research team
- Not about one person



## Processes of Co-Production



- Different from usual research
- Flexibility
- Develops as you go
- Open about every decision made

Team members continue to

- Improve in co-production
- Use resources to learn more (Easy Read booklets)



## Processes of Co-Production



### **Ethics Committee Chair Insight**

“The ethics process is not simply filling in a form. Instead, it’s about setting up a whole story around how the research came to be.”



## Roles in Co-Production

- Be clear about the roles of co-researcher and participant
- Role names vary - for example:

- |  |   |
|--|---|
| <ul style="list-style-type: none"><li>• advisor</li><li>• consultant</li><li>• co-researcher</li><li>• lived-experience researcher</li></ul> | <ul style="list-style-type: none"><li>• subject matter expert</li><li>• expert by experience</li><li>• peer researcher</li><li>• community researcher</li></ul> |
|--|---|







## Benefit and Risk in Co-Production

### Benefits:

- Skills development (e.g., body mapping)
- Give a voice to people with disability
- Real-world impact



### Risks:

- Can be a negative experience for people with disability



## Benefit and Risk in Co-Production



### **Ethics Committee Chair Insight**

“The nature and culture of ethics committees is that they tend to incline towards attention to risk over benefit. I think concerns around vulnerability and harm often carry more weight than benefits around inclusion, broadly speaking.”



## Vulnerability and Capacity in Co-Production



### Vulnerability

- Understood by ethics committees as protective of people
- BUT people with disability see it as
- Taking their rights away
  - Unfair
  - Disheartening



## Vulnerability and Capacity in Co-Production

### Capacity



- United Nations Convention on the Rights of Persons with Disabilities **assumes capacity** (article 12)
- Co-researchers often work on ethics applications
  - They read the language about them

ALPHA-THALASSEMIA / MENTAL RETARDATION SYNDROME, CHROMOSOME 16-RELATED; NEURODEGENERATION, CHILDHOOD-ONSET, WITH HYPOTONIA, RESPIRATORY INSUFFICIENCY, AND BRAIN IMAGIN; DEAFNESS, CONRIBA; ABNORMALITIES; CONRIBA; CHROMOSOME 16 DELETION SYNDROME; INTELLECTUAL DEVELOPMENTAL DISORDER, X-LINKED; COFFIN-LOWRY SYNDROME; CLS; MENTAL RETARDATION, X-LINKED, SYNDROME; JMS; BROOKS-WISNIEWSKI-BROWN SYNDROME; MENTAL RETARDATION, DEAFNESS, AND MICROGENITALISM; ME; MIC, BROOKS-WISNIEWSKI-BROWN TYPE; MRXSBWB; CHROMOSOME Xp11.22; MENTAL RETARDATION AND MACROCEPHALY SYNDROME; NEURODEGENERATION, WITH HYPOTONIA, RESPIRATORY INSUFFICIENCY, AND BRAIN IMAGIN; CONRIBA; COFFIN-LOWRY SYNDROME; CLS; CHROMOSOME Xp11.22 DUPLICATION SYNDROME; RATION, CHILDHOOD-ONSET, WITH HYPOTONIA, RESPIRATORY INSUFFICIENCY, AND BRAIN IMAGIN; ABNORMALITIES; CONRIBA; ALPHA-THALASSEMIA/MENTAL RETARDATION SYNDROME, CHROMOSOME 16-RELATED; CHROMOSOME Xp11.22 DUPLICATION SYNDROME; MACROCEPHALY SYNDROME; NEURODEGENERATION, CHILDHOOD-ONSET, WITH HYPOTONIA.



**I am not a number.**

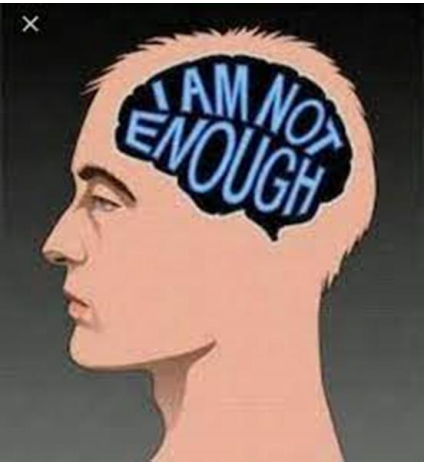
**Labels are for jars - not people.**





It is very important that we use

- Respectful language



Negative language can make people feel

- Sad
- Not part of the group



## Quality in Co-Production



- Co-production makes projects better
- No research on how to judge the quality
- 2 types of quality
  - Collaboration
  - Outcomes



## Building Better Practice in Ethical Co-Production

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- Ethical governance
- Research cultures
- Institutional infrastructure
- Research funding and commissioning

# Our Experiences with Co-production



Everybody is valued

We play to our strengths

Decisions are made together at every stage



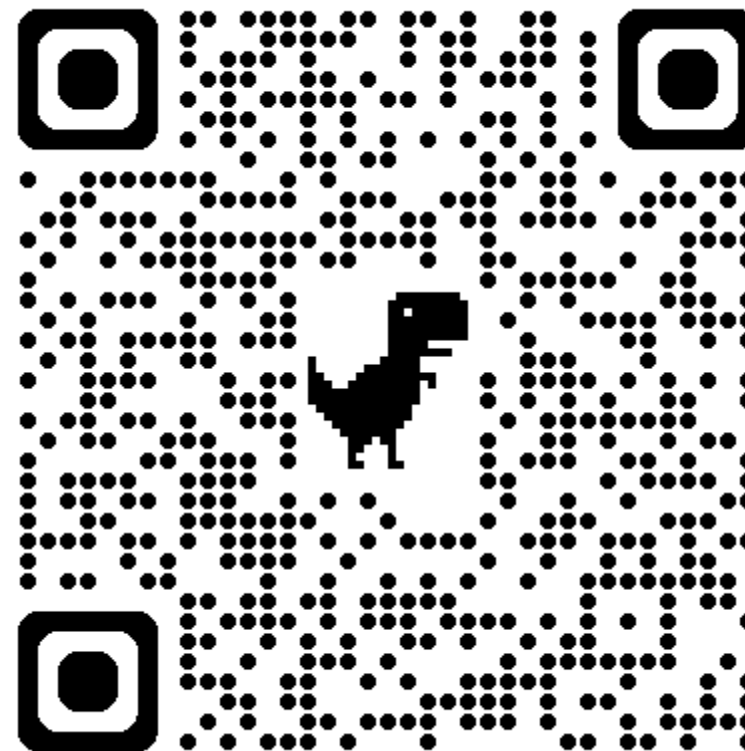
Capacity is

- Assumed
- Reasonable adjustments are made
- Easy Read documents, recorded Minutes



Time for  
questions

Scan the QR code to  
download the resources



[www.disabilityinnovation.unsw.edu  
.au/inclusive-research/guidelines](http://www.disabilityinnovation.unsw.edu.au/inclusive-research/guidelines)