DOING RESEARCH INCLUSIVELY:

Co-Production in Action







UNSW Disability Innovation Institute

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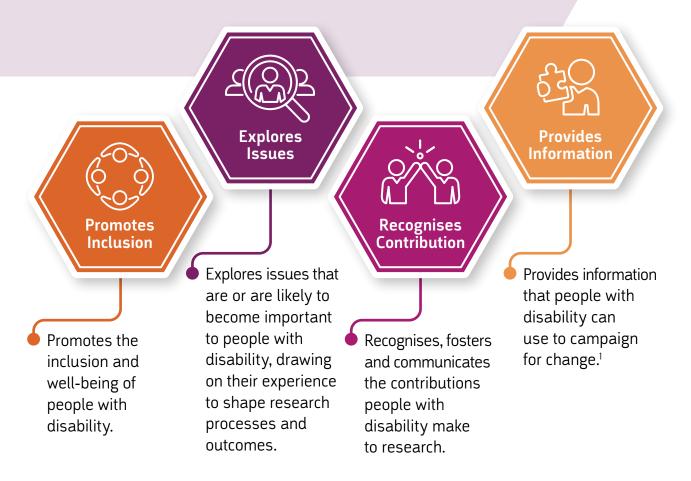
UNSW Disability Innovation Institute

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Inclusive Research Practice and Co-Production

The Disability Innovation Institute at UNSW Sydney is committed to a process of co-production to underpin our approach to inclusive research. In inclusive research, people with disability are involved not just as participants, but as co-creators of knowledge. The Disability Innovation Institute recognises that inclusive research:



We understand co-production as a process of collaboration and collective decisionmaking, which involves changing the relations of research traditionally separating users and producers.² Our approach aims to create a shared community of practice in which all stakeholders have a role in knowledge creation.³ Our ethos is aligned with the fundamental values of co-production in emphasising genuine powersharing and a democratisation of relationships between the different individuals, groups and institutions involved.⁴

2 Durose, Needham, Mangan, & Rees, 2017, p. 135.

4 Fisher, 2016.

¹ Walmsley, Strnadová, & Johnson, 2018.

³ Ryecroft-Malone, Burton, Bucknall, Graham, Hutchinson, & Stacey, 2016.

Purpose of the Guidelines

Doing Research Inclusively: Co-Production in Action has been developed as a companion to Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability. It has been developed for academic researchers at UNSW Sydney and beyond, people with lived experience of disability, disability organisations, and other stakeholders who understand and appreciate the importance of co-producing research together with people who have lived experience of disability.

Doing Research Inclusively: Co-Production in Action addresses the research process in depth and provides practical guidance to help researchers wanting to use co-production in their research. Readers are encouraged to refer to *Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability* to understand the benefits, principles, and strategies of co-production. The current guide – *Doing Research Inclusively: Co-Production in Action* – provides detailed consideration of co-production activities across the different stages of the research process.

Terminology

The co-production of disability research brings together people from a range of different and potentially intersecting groups, including but not limited to people with disability, their families and supporters, representatives of disability organisations, practitioners, service providers, and professional researchers. These can be differentiated as academic or professional researchers and co-researchers.

We use the term 'co-researchers' to refer to individuals involved in the coproduction of research who represent any of the groups mentioned above based outside of academic or research institutions. In this sense, 'co' suggests an equal but different contribution and has the implication of 'collaborative'. There are other terms used in Australia and internationally, such as 'community researchers' or 'participatory researchers'.

Co-Production in the Research Process

Any type of research – qualitative, quantitative, or mixed-method – can make use of co-production. There are opportunities for co-production in every phase of research and researchers can draw on different activities of coproduction in different phases. A simple model of research is set out across six phases in the following diagram.

INITIATING

This phase brings the research idea to life. In this process the team arrives at a joint understanding of the research topic.

Initiating

PLANNING

In this phase the research is designed. Two sets of related decisions are made:

Planning

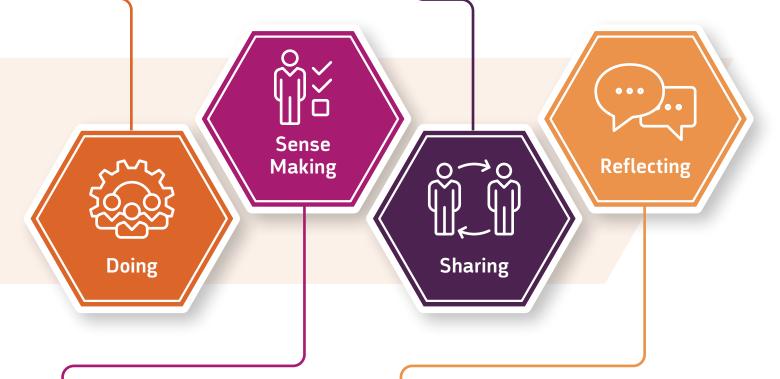
- 1. decisions about what the research will look like, and
- 2. decisions about how co-production will happen.

DOING

In this phase, the research and coproduction plan is activated. Research activities can include applying for ethics approval, recruiting participants, and field work to collect data. Co-production activities can include co-researchers identifying and working with key groups for engagement and recruitment, co-developing research instruments (e.g., interviews and survey questions), and collaborative data collection.

SHARING

In this phase the findings go public. Co-production can broaden the places and ways in which research is shared. Research activities in this phase include developing outputs to communicate research findings to diverse audiences. Co-production activities include identifying the audiences and deciding the best ways and formats to use to communicate the findings.



SENSE MAKING

This phase is about making sense of the data and understanding what it reveals about the topic. Research activities in this phase include data analysis (descriptive, thematic, or statistical), the development of key insights from the data (findings), and interpretation of the findings to provide answers to the research questions and set directions for change.

REFLECTING

In this phase what has been learnt from the co-production process and the implications for co-production in future projects are considered. It is important to think not only about what worked well but also about what did not go according to plan. In the Reflecting phase the experience of the relationship between academic researchers and co-researchers should be discussed openly and honestly.



This phase brings the research idea to life.

In this process the team arrives at a joint understanding of the research topic.

Ideas for research can be generated in different ways:

- Researchers might see a gap in the existing research;
- People with disability and their organisations might see a need for research;
- Funding bodies might seek proposals or commission research about specific topics.

It is important for the academic researcher to be clear about their reasons for undertaking research focused on and potentially involving people with disability. Just because a researcher thinks a topic is a good idea, it does not mean that people with disability and their organisations will share this view. A key co-production activity in the initiation phase, however the idea comes up, is that academic researchers and people with disability and their organisations discuss and agree on the importance and relevance of the research idea.

Relationships are a central concern in co-production

An important focus throughout the co-production process is on the relationship between the academic researcher and the co-researcher. This will require more conscious attention and negotiation than conventional academic relationships because of the unequal distribution of power in the relationship. Developing effective and respectful ways of communicating is a key part of establishing and developing the relationship.



How do we know that the research idea is of relevance to people with disability?

It might be that a disability organisation already identified the research idea as an important topic. Alternatively, an academic researcher may have noted a gap in the research literature that represents an opportunity to increase knowledge about a topic.

How do we develop research partnerships with people with disability and their organisations?

Developing research partnerships does not happen overnight. Some researchers may have existing relationships with people with disability and their organisations, others may not. Co-production is based on genuine and authentic relationships⁵ and a shared interest in positive change for people with disability. Forming partnerships requires a significant investment of time and energy but the potential benefits to academic researchers, people with disability, and their organisations are considerable.

How does the research idea benefit people with disability?

It is important to speak directly with people with disability and their organisations to understand whether and how the research idea has the potential to benefit them. In this phase, the academic researcher does not come with a fully developed proposal. Instead, they may bring an initial idea, which is tested, negotiated, and refined⁶ to ensure it is grounded in the interests and concerns of the organisation or group.

⁵ Raman and French, 2021

⁶ Nierse and Abma, 2011



What co-production can look like

Co-production in the Initiating phase can include:

- Adopting a respectful and relationship-based approach to research;
- Collaborating in the process of generating and refining research ideas;
- Conceptualising research relevant to the lived experience of disability;
- Aiming towards research beneficial to everyone involved;
- Prioritising consensus amongst stakeholders.

What co-production can contribute

- Increasing connection between universities, people with disability and disability organisations;
- Foregrounding the voices of people with disability in the generation of research ideas about them;
- Grounding research in the lived experience of disability;
- Focusing research on issues relevant to people with disability and their organisations;
- Adding credibility to academic research that is carried out with people with disability and their organisations.

Co-production outcome: Co-initiated research topic

Accessibility considerations

As well as physical accessibility, which of your documents need to be in Easy Read? Do you have a budget for Easy Read documents? Consider having a member of the team do an Easy Read short course, to develop the skills and capacity of the whole research team.

Thinking about roles⁷

Academic researcher role

- Identifying the gaps in the literature
- Valuing the lived experience perspective on the research issue
- Initiating and maintaining academic, industry and community networks and partnerships
- Defining and modelling the research relationship
- Negotiating relationship boundaries

Co-researcher role

- Discussing the research issue identified by people with disability
- Shaping the research questions from a lived experience perspective
- Establishing a co-researcher identity
- Negotiating relationship boundaries



In this phase the research is designed.

Two sets of related decisions are made:

Decisions about the research can include:

- What have others said about the topic?
- What are the research questions?
- What is the best way to approach and investigate the topic (methodology)?
- Who are the participants and how many participants are needed (sample)?
- How are the participants best engaged (recruitment)?
- What do we ask them and how do we ask it (research instruments)?
- How will we make sense of what they tell us (data analysis)?
- Who needs to know what we found out (target audience)?
- In what formats do we collect the information (methods) and make it public (accessibility, dissemination)?

Decisions about the process of co-production can include:

- How will decisions be made?
- How will any conflicts of interest or differences of opinion be resolved?
- Who will do what (roles in the project)?
- What kinds of support are needed?
- How do we ensure safety of all team members?
- How do we share what we find out?

Roles in the project

In co-production, roles may shift and develop over the course of the project. However, discussing roles in a transparent and open way⁸ at the Planning phase is central to deciding how power and decision making is going to be shared across the phases of the research project. The successful negotiation of roles will lead to a clearly defined research team.

8 Nind, 2014

Key questions

Who should partner in the research?

Engaged and meaningful consultation is critical at this phase. Here considerations can include: who in the disability community has an interest in the research area and which disability organisations could be approached to partner in the research.

How will the project be funded?

The considerations may include: where funding comes from, who can apply for the funding, what are the requirements of the funding, and what sorts of partnerships are required. Here the costs of co-production must be included in the budget, including payment to co-researchers, costs of training and accessibility supports.

What are the responsibilities?

External constraints, like university or funder rules and expectations, may influence the roles of academics and co-researchers at this point. For this reason, co-production requires forethought and strategic planning to have the co-production infrastructure in place. The academic researcher is responsible for ensuring that the research meets the expectations and requirements of the university. The community partners are responsible for accountability to their organisation and its members.

What training and support do all partners need to undertake the research?

Each research team will have their own training and support needs.⁹ Often academic researchers take responsibility in co-production for providing training related to the research process to co-researchers. An assets and training reflection might be useful at this phase. See Appendix A for an example.



What co-production can look like

Co-production at the Planning phase can include:

- Funding applications that are jointly developed;
- Discussing openly how the project will use co-production;
- Developing co-production agreements between partners that are clear and accessible;
- Engaging with other disability stakeholder groups;
- Formulating research questions shaped by the lived experience of people with disability.

What co-production can contribute

- Developing research plans informed by the experience of people with disability;
- Foregrounding of the concerns and interests of people with disability and their communities in the project;¹⁰
- Recruiting approaches guided by lived experience insights into the participant group;
- Piloting selected methods with co-researchers and receiving immediate feedback.

Potential co-production outcome: Co-designed research

10 Strnadová et al., (2020)

Co-production agreement

Developing a co-production agreement to which all team members can refer at any stage of the project can be a useful thing to do. The agreement would set out the general agreed approach to decision making and to resolving any conflicts of interest or disagreements. See Appendix B for an example.

Mutual support in co-production

At each phase the following types of support should be considered:

Practical
 Emotional
 Research

The type and level of support required will differ depending on the support needs of the individual members of the research team. Support will also depend on the composition of the research team and the level of involvement that has been negotiated at each phase of the project.

Co-producing a literature review

Burke et al. (2003) report on an inclusive review of the academic literature. Coresearchers who were willing were given select journal articles and were asked to read the article with support, and summarise its key arguments and present them to the other members of the research group either verbally or in written form.

Time considerations

Have you considered the time needed for co-production? Co-production adds both time and benefits to a research project. Has additional time been built into your project plan? Different phases will require different amounts of time.¹¹ The Initiating and Planning phases will require more time, but once the coproduction relationship is established project time will also be more efficient.

In this phase, the research and co-production plan is activated.

Research activities can include applying for ethics approval, recruiting participants, and field work to collect data. Co-production activities can include co-researchers identifying and working with key groups for engagement and recruitment, co-developing research instruments (e.g., interviews and survey questions), and collaborative data collection.

Safety in co-production

Safety is an important consideration in co-production. Co-researchers by virtue of their lived experience have greater proximity than most academic researchers to the challenging stories that participants may share. Co-production requires the consideration of a trauma informed approach to research which prioritises the principles of safety, choice, collaboration, empowerment, and trustworthiness¹² in all phases of co-production.

Collecting data on co-production

Co-production is still quite new as a research approach. It is important to share knowledge and experiences in co-produced projects. In addition to collecting the research data it is also important to collect data about the co-production process itself, for example in the form of team meeting minutes, audio-recorded reflective fieldnotes, and debriefings. This can make a valuable addition to any project outputs or publications and add to the body of knowledge about co-production.

12 Keesler, 2020

Doing

Key questions

What are the ethical and safety issues related to co-production in the research?

Co-researchers with disability bring their lived experience perspective and awareness of how to understand and approach disability related issues, which are often in addition to the concerns of ethics committees. Capturing these issues in formal ethics applications as they are to be operationalised in the data collection will help ethics committees understand co-production methods better.

What is the added value of co-researchers collecting data?

Co-researchers undertaking fieldwork can be beneficial to a project in several ways. These include providing insights into how best to approach the participant group, and providing choice to participants who may feel more comfortable talking to someone with similar lived experience. Co-field work can help to demonstrate the integrity and care taken in the research process towards participants. Co-researchers may also provide an insider perspective on whether data collection instruments are fit for purpose.

What are the potential risks to co-researchers in doing fieldwork?

It is important to consider whether participants' stories are likely to be traumatic or potentially triggering for co-researchers. A risk assessment protocol or safety plan can assist the whole team in making informed decisions about co-researcher roles in data collection. Ethical considerations are also relevant in situations where participants are personally known to the co-researcher.



What co-production can look like

Co-production at the Doing phase can include:

- Informing ethics applications through disability lived experience;
- Recruiting in ways that are ethical, sensitive, and safe;
- Collecting data with flexibility to suit the project, research team, and participants;
- Co-collecting data in accessible ways.

What co-production can contribute

- Enhancing ethical disability research practice;
- Increasing accessibility to academic research processes;
- Anticipating and avoiding potential barriers to successful research;
- Informing approaches to participant safety;
- Making fieldwork accessible through building capacity of all team members.

Potential co-production outcome: co-produced research



This phase is about making sense of the data and understanding what it reveals about the topic.

Research activities in this phase include data analysis (descriptive, thematic, or statistical), the development of key insights from the data (findings), and interpretation of the findings to provide answers to the research questions and set directions for change. Co-production activities such as forming lived experience data analysis reference groups¹³, using forms of visual data representation to improve accessibility¹⁴, and participatory video approaches¹⁵, are some of the possible ways to foreground the perspective of people with disability in the analysis and interpretation of data.

Working together on data analysis

There are many ways that data can be explored and understood collaboratively. Here it is important that data are accessible for co-researchers, and so consideration of how to deal with long transcripts or statistical data are critical. Creative solutions can be workshopped within the team to suit the needs of co-researchers. There is also the added benefit that co-production encourages academic researchers to be innovative and take risks, and potentially gain additional insights into the data in the process. For example, numerical data can be presented in different visual formats and analysed using focus groups.¹⁶

13 For instance, to undertake inclusive data analysis Koenig (2011) formed a reference group of people with intellectual disability to collectively analyse the life stories of participants.

- 14 Kramer et al., 2011.
- 15 Sitter, 2015. For other examples see, Butler et al., 2012; and Stevenson, 2014.
- 16 Kramer et al., 2011.



• Key questions

To what extent are the data analysis methods accessible?

Not all data analysis processes may be accessible to all co-researchers. Discussion amongst the whole team as to whether and how different elements of the analysis and interpretation are amenable to co-production can enhance the quality of data analysis. Similarly, discussion about the ways adaptations should be made to the data analysis approach will maximise co-researcher involvement.¹⁷

How are the findings understood from the lived experience perspective and what does it mean for change to benefit the lives of people with disability?

Co-production aims to democratise the research process. It also seeks to facilitate positive change for people with disability. Researchers using co-production are motivated by the desire to see benefits and improvements in the lives of participants. It is important to frame the findings in a way that is respectful of and sensitive to the lived experience of people with disability.

What are the potential risks to co-researchers in analysing data?

As with data collection, data analysis can also mean a prolonged period dealing with potentially traumatic experiences shared by participants, which may be distressing for co-researchers. A risk assessment protocol or safety plan can assist the whole team in making an informed decision about co-researcher roles in data analysis.

17 Kramer et al., 2011 demonstrated a process of data analysis used by university researchers and self-advocates in inclusive research. All members participated in data analysis but not everyone participated in data interpretation.



What co-production can look like

Co-production at the Sense Making phase can include:

- Diversifying perspectives on the data;
- Involving co-researchers in generating and checking themes;
- Providing additional layers of reliability to academic researcher interpretations of the data.

What co-production can contribute

- Deeper analyses of the data;
- Findings that are relevant, relatable, and resonant with the experiences of people with disability;
- Adapting traditional data analysis methods in novel ways;
- Communicating research processes and findings in accessible ways to reach a broader audience.

Potential co-production outcome: co-sense making



In this phase the findings go public.

Co-production can broaden the places and ways in which research is shared. Research activities in this phase include developing outputs to communicate research findings to diverse audiences. Co-production activities include identifying the audiences and deciding the best ways and formats to use to communicate the findings. This can be captured in a co-produced dissemination/knowledge exchange plan. See Appendix C for an example.



Co-sharing

In recent research about belonging in the lives of people with disability¹⁸, co-researchers made a short video to discuss the findings of the research and they were also lead authors on an article describing the co-production experience and process.¹⁹ In another example, members of a self-advocacy group and an academic researcher co-authored an article about their research.²⁰ In another piece of research, committee members with intellectual disability and their support worker authored a journal article without the input of academic researchers.²¹

18 Renwick et al., 2019

19 Stanley et al., 2019

20 Hollomotz and The Speakup Committee, 2008

21 Deguara et al., 2012



Who needs to hear about the findings of the research?

In co-production the potential audience for the research is broad, and therefore the dissemination/knowledge exchange strategy needs to be carefully and collaboratively planned. Co-production is primarily concerned with positive change, and so the active involvement of people with disability in sharing the research is important. Partnerships and relationships already established with disability organisations and their members mean that audiences who might not otherwise access research will be able to engage with it.

How will the research findings be shared with diverse audiences?

Generally, university and external funders will have expectations about how the research is shared. Co-production has a place in both traditional ways of sharing, like journal articles²² and conference presentations, and in other modes such as videos, podcasts, art exhibitions, or theatre performances. Questions such as who writes what and for which purpose need to be transparently negotiated in the research team rather than assumed.

How can knowledge about and experience with the co-production process be shared with others?

Asking co-researchers how best to reach their diverse communities is important, as is engaging with disability organisations and their networks. Co-production is still a relatively new approach to undertaking research. Therefore, it is important to share the experiences of research team members with and without disability of the co-production process, to support other researchers and organisations considering co-production. Co-production is dynamic, and much learning occurs by doing, so it is valuable and important to share what has been learnt. Consider a publication describing the co-production process used in the research and reflecting on the value of co-production and its challenges.

22 For examples see Hollomotz and The Speakup Committee, 2009; Deguara et al., 2012



What co-production can look like

Co-production at the Sharing phase can include:

- Producing Easy Read documents with findings;
- Presenting together at conferences;
- Co-authoring journal articles;
- Making a video overview of the findings;
- Sharing the findings with disability organisations and their members.

What co-production can contribute

- Disseminating the research in a more accessible way via grassroots networks;²³
- Generating impact for research findings by reaching a wider and more varied audience;
- Enhancing the authenticity and credibility of the research findings;
- Highlighting the relational dimensions of quality research.

Potential co-production outcome: co-sharing

23 Strnadová et al., 2020; Community Mental Health Drug and Alcohol Research Network, 2015



In this phase what has been learnt from the co-production process and the implications for co-production in future projects are considered.

It is important to think not only about what worked well but also about what did not go according to plan. In the Reflecting phase the experience of the relationship between academic researchers and co-researchers should be discussed openly and honestly. Candid conversations will allow all members of the research team to grow and develop. Lessons learnt about the co-production process will be critical for other research teams to further evolve the practice of co-production in disability research more generally.



Key questions

What went well?

Both formal and informal approaches can be used to evaluate the process of co-production in the project. Areas to consider may include the approach taken, how co-production has assisted in meeting the expectations of all stakeholders (e.g., university, funders, and disability organisations), and interpersonal and relational aspects of the research project.

What could be done better?

The capacity to critically reflect on both the research process and the relationships within it is important. Being honest and realistic about the co-production process and the challenges encountered can help to strengthen the approach to co-production in future research.

What do we do next?

It is important to think about what comes after the completion of a project. Consider how future research projects might build on the completed project and how co-production can enhance the quality of these projects.

What was the added value of co-production²⁴ to the project?

The contribution of a co-production approach should be considered to understand how and in what ways the project design, objectives, outcomes, and impact have been enhanced.

24 Walmsley et al., 2018



What co-production can look like

Co-production at the Reflecting phase can include:

- Sharing the successes and shortcomings;
- Reflecting on the co-production experience in real time;
- Discussing what inclusion looked and felt like in the co-production process.

What co-production can contribute

- Developing new skills and opportunities for personal growth for academic researchers²⁵ and co-researchers;
- Enduring research partnerships between universities and disability organisations;
- More nuanced understanding of the disability experience;
- Adding depth and authenticity to the project.

Potential co-production outcome: co-learning

Evidence Base

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Appendix A

Assets and Training Reflection²⁶

Putting co-production into practice involves a range of co-production activities. This reflective tool can assist the research team to think about what they bring to the co-production process and what benefits will flow from working together.

- **1. Assets:** What are the personal strengths and research skills of each member of the team?
- **2. Capacity:** What is the contribution (time and experience) each member can make to the team?
- **3. Shared roles:** What are the activities within the project that can be shared between team members?
- **4. Networks:** What are the networks that each team member brings to the project and how can they be connected and expanded?
- **5. Mutuality:** How can the research team support one another (utilising internal and external resources) to maximise assets, capacity, shared roles, and networks?

26 Adapted from: https://www.seemescotland.org/media/7287/co-production-self-assessment-framework.pdf

Appendix B

Co-Production Agreement

PROJECT TITLE:		Discussed	Agreed
Project description	This co-produced research project aims to address		
About your role	 Timeframe Pay and conditions Scope/activities of the role 		
How will decisions be made?	 Distinction between non- negotiable and negotiable roles Negotiated process with attention to power differentials 		
How will any conflicts of interest or differences of opinion be resolved?	 Reference to formal and informal processes Attention to addressing the power differential in relation to disagreements or conflicts 		
Who will do what (roles in the project)?	• Discuss potential roles across the 6 phases, and how these may change over the life of the project		
What kinds of support are needed?	 Training Practical Mentoring Support people 		
How do we ensure safety of all team members?	 Where appropriate, formal and informal supports for academic and/or co-researchers identified All aspects of this agreement discussed and agreed All protocols governed by principles of trauma informed practice 		

Appendix C

Dissemination Plan for Co-Produced Research

PROJECT TITLE:	
Project description	This co-produced research project aims to address
Purpose of sharing this research	 Raise awareness – let others know what you are doing? Inform – educate through sharing? Engage – form relationships and get feedback through sharing? Activate – increase awareness of the need for social change? Promote – raise the profile of your research?
The target audiences to share with	 Who do academic researchers think it is important to share with? Who do co-researchers think it is important to share with?
Main message or messages to be shared	 What are the most important findings to share with different target audiences? In what ways can sharing also promote the co-production elements of the project?
The chosen methods to share the messages	 How will the findings be made accessible to each of the target groups? What novel approaches might be used (Podcasts, videos, webinars, social media, self-advocacy groups)?
Timing for sharing	• Develop a realistic timeline for sharing with reference to funder's requirements and in consultation with co-researchers
Evaluating success of sharing	 How will you measure the success of your sharing? What relationships have been created/maintained during the sharing process?
Resources required for sharing	 Financial Personnel Skills Technology

For more information and further resources visit: www.disabilityinnovation.unsw.edu.au





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