Doing Research Inclusively: Guidelines for   
Co-Producing Research with People with Disability

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### Acknowledgements:

We extend thanks to Australia’s leading disabled people’s organisations, disability representative organisations, co-researchers with disability, and academic researchers with expertise in inclusive approaches to research, who contributed to discussion and debate about the issues presented in these Guidelines.

Our thanks to Lew Keilar for the live capture illustrations. [www.lewkeilar.com](http://www.lewkeilar.com)

### ****Guidelines prepared by:****

Professor Iva Strnadová  
Professor Leanne Dowse  
Chloe Watfern, Research Assistant

### ****To cite the Guidelines:****

Strnadová, I., Dowse, L., & Watfern, C. (2020). Doing Research Inclusively: Guidelines for   
Co-Producing Research with People with Disability. DIIU UNSW Sydney.

### Contact:

Disability Innovation Institute  
UNSW Sydney  
[diiu@unsw.edu.au](mailto:diiu@unsw.edu.au)  
(+61 2) 9385 9114

Table of Contents

[Inclusive Research Practice and Co-Production - 4 -](#_Toc43973715)

[Purpose of the Guidelines - 5 -](#_Toc43973716)

[Terminology - 5 -](#_Toc43973717)

[Benefits of Co-Production - 6 -](#_Toc43973718)

[Benefits for production of knowledge and impact. - 6 -](#_Toc43973719)

[Benefits for co-researchers with disability. - 6 -](#_Toc43973720)

[Benefits for academic researchers. - 6 -](#_Toc43973721)

[Benefits for organisations involved. - 6 -](#_Toc43973722)

[Principles of Co-Production - 7 -](#_Toc43973723)

[Strategies of Co-Production - 8 -](#_Toc43973724)

[Creating a Research Project - 8 -](#_Toc43973725)

[Agenda setting - 8 -](#_Toc43973726)

[Leadership - 8 -](#_Toc43973727)

[Budgeting & Resources - 8 -](#_Toc43973728)

[Recruiting co-researchers - 8 -](#_Toc43973729)

[Payment: How should co-researchers be paid? - 9 -](#_Toc43973732)

[Conducting a Research Project - 10 -](#_Toc43973733)

[1. Planning and Running Meetings - 10 -](#_Toc43973734)

[2. Providing Training - 11 -](#_Toc43973736)

[3. Navigating Ethics - 11 -](#_Toc43973737)

[4. Joint Ownership of Key Decisions - 11 -](#_Toc43973738)

[5. Ongoing Support for the Team - 11 -](#_Toc43973739)

[Evaluating the Impact of a Research Project - 13 -](#_Toc43973743)

[Evidence Base - 14 -](#_Toc43973744)

[Suggested Resources - 16 -](#_Toc43973745)

[Appendix A - 18 -](#_Toc43973746)

[Co-Produced Research: Budget Template - 18 -](#_Toc43973747)

[Appendix B - 19 -](#_Toc43973748)

[Project Information Template - 19 -](#_Toc43973749)

# 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:

1. Promotes the inclusion and well-being of people with disability.
2. Explores issues that are or are likely to become important to people with disability, drawing on their experience to shape research process and outcomes.
3. Recognises, fosters and communicates the contributions people with disability make to research.
4. Provides information that people with disability can use to campaign for change.[[1]](#footnote-1)

We understand co-production as a process of collaboration and collective decision-making, which involves changing the relations of research traditionally separating users and producers.[[2]](#footnote-2) Our approach aims to create a shared community of practice in which all stakeholders have a role in knowledge creation.[[3]](#footnote-3) Our ethos is aligned with the fundamental values of co-production in emphasising genuine power-sharing[[4]](#footnote-4) and a democratisation of relationships between the different individuals, groups and institutions involved.[[5]](#footnote-5)

# Purpose of the Guidelines

*Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability* has been developed for academic researchers at the University of New South Wales (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.

This document draws on a comprehensive review of contemporary evidence in co-production. It was developed drawing on the views and experience of a range of Australia’s leading disabled people’s organisations and disability representative organisations together with disability researchers with expertise in inclusive approaches to research, and was particularly informed by input from participants in a workshop on co-production in disability research held at UNSW Sydney on 12 November 2019.

### 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 co-production 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’, to name just two.

# Benefits of Co-Production

Co-production has been shown[[6]](#footnote-6) to have a range of benefits for research stakeholders and for the production of knowledge more generally:

### Benefits for production of knowledge and impact.

The involvement of people with disability and their communities can benefit knowledge production at many stages of the research process. For example, co-researchers with disability might anticipate barriers to participants with disability. In research teams grounded in co-production, research outputs tend to be shared in a more accessible manner and disseminated via the co-researchers’ grassroots networks.[[7]](#footnote-7) The co-production of research can help to ensure that the concerns and interests of people with disability and their communities are *central* to a research project, increasing opportunities for real-world *impact*.[[8]](#footnote-8)

### Benefits for co-researchers with disability.

The co-production process itself can be a very positive one for people with disability. Research has shown that involvement in the co-production of research has the potential to: (a) empower individuals; (b) give voice and build self-advocacy; (c) provide training, skills and new job opportunities; (d) generate mutual understanding with peers and other team members; and (e) forge long-lasting networks and friendships.[[9]](#footnote-9)

### Benefits for academic researchers.

For academic researchers, the co-production process can be an opportunity for personal growth and the development of new skills. For example, the process can help researchers better understand the community they are producing knowledge with and about, while learning new ways of putting knowledge into action.[[10]](#footnote-10) It can also lead academic researchers to rethink (or reframe) their values, for example by moving towards a human rights perspective.[[11]](#footnote-11)

### Benefits for organisations involved.

The co-production of research can be a chance to facilitate change within organisations through the development of stronger relationships with communities and/or service users. What’s more, the co-production of research can help bring funding to organisations via new avenues.[[12]](#footnote-12)

# Principles of Co-Production

Co-production is best understood as a set of guiding principles. It is not a one-size-fits-all approach, nor a strict model with a fixed set of tools or techniques.[[13]](#footnote-13) Rather, it presents a pathway towards an ideal of authentic collaboration and power-sharing between academic researchers, people with disability, and other relevant organisations, individuals and communities. Good co-production involves finding ways of working together that as far as possible suit everybody.[[14]](#footnote-14)

A number of existing guidelines suggest underlying principles that should inform co-production. For a list of these see the *Suggested Resources* section at the end of these Guidelines. The following is a summary of the key principles distilled from the literature.

* **Power-sharing.** Power differentials between individuals and groups need to be acknowledged and actively managed. There can still be leaders, and people will necessarily play different roles within the research process. However, projects should be founded on a sense of shared responsibility and joint ownership, with methods in places to ensure collective control over the direction of the project.[[15]](#footnote-15)
* **Diversity.** Different perspectives and skill sets are brought together in co-production. It is important that all voices are heard and treated with respect. There are many different types of expertise, and all can be valued for their contribution to research. Individuals can also choose to become involved in the aspects of research that best suit their interests, skills and expertise.
* **Accessibility.** In order to be inclusive, organisations and individuals must address barriers that may prevent or discourage involvement in co-production. The research process must be accessible. Accessibility can mean ensuring physical access. It can also mean making sure that all information relevant to the research project is made available to be shared in an appropriate way.
* **Reciprocity.** Everybody should benefit from co-producing research. Financial recognition of time, expertise and effort is one way that people can be valued for their contribution. The process of co-production itself can be of value for all stakeholders: for example, learning from each other, building new relationships and skill sets, working towards social goods.
* **Transparency.** Co-production should be built on a shared understanding of the context, goals, scope and process, each person’s role, and of potential outcomes. Ongoing, open communication and the building of trusting relationships help to maintain transparency. It is important to be open about and reflect on different knowledge and assumptions that individuals bring to a research project throughout the co-production process. For example, an academic researcher might bring advice on particular research methods and data analysis, while a person with a disability might bring knowledge of their community.[[16]](#footnote-16)

# Strategies of Co-Production

Co-production can be embedded throughout the research process – from agenda-setting and securing funding, to conducting and disseminating research. Here, we present some ideas about ways of making co-production work, broken down according to different stages of a project.

## Creating a Research Project

### Agenda setting

At the heart of co-produced research is the process of co-design, where all involved parties make decisions about the focus and aims of an inclusive research study, and about how these aims can be achieved. This stage also includes applying for funding and forming a team. Frameworks for collective brainstorming, for example deliberative dialogue processes, can provide a useful tool for reaching consensus on research topics and questions.

### Leadership

A co-produced research project can be led by individuals representing different, potentially intersecting groups, including community members with disability, academic researchers, practitioners and/or service providers. An ethos of co-production does not require that research is led by an individual with a disability, but this can certainly be the case.[[17]](#footnote-17) The leadership of a project should represent each core group who has a stake in the research. We acknowledge that the requirements of certain funders or institutions might mean that there is a sole named person as the leader. However, that can still mean that there is more collaborative leadership in practice.

### Budgeting & Resources

Co-production takes time, and resources, to be successful.[[18]](#footnote-18) Thus time and resources need to be factored into the project plan from the very beginning. Simple things to be considered include catering for meetings (snacks are a great way of bringing people together), venue hire, covering the cost of travel and accommodation, remuneration for co-researchers (see *Appendix A*).[[19]](#footnote-19)

### Recruiting co-researchers

Organisations might establish, or already have, a research reference group that is not attached to a specific project. These groups made up of people with disability (and, if relevant, other stakeholder groups too) can provide input into research strategy and agenda setting, and also be part of ongoing training. These reference groups can also serve as a pool of potential co-researchers for specific projects.[[20]](#footnote-20)

### Things to Consider when Working with Co-Researchers:

### Who should be on the team?

* The kinds of groups which need to be represented on the team and the attributes they should have, will depend on the nature of the project. These are important questions to ask in order to ensure a transparent process of recruitment and appointment of co-researchers.
* There is a concern that ‘hard to reach’ groups are not well represented as co-producers of research.[[21]](#footnote-21) Use the full range of available networks to reach people who may not otherwise be involved (e.g. due to socio-economic, cultural or circumstantial disadvantage).
* How many people should be involved? It is important that there is a clear rationale and justification for the inclusion of each team member, with a clear role description. Each project will have a different optimum number of people involved.

Clear and concise details about the project should be provided in any information shared with potential co-researchers. This may include role specifications, information about what training and support will be provided, time commitment, and covering the costs of undertaking the role of a co-researcher (see *Appendix B*).

### Payment: How should co-researchers be paid?

* It is important that people are properly recognised for the time and effort they put into the co-production of research. This is particularly important for co-researchers with disability who are not engaged in the project as part of their regular professional duties.
* Differences in recognition and remuneration for input into the project can have a significant effect on power dynamics within a group. Paying co-researchers with disability for their involvement will also help recruit a more diverse group of people.
* If co-researchers with disability are already employed by a partner organisation, the project budget allocation will recognise partner organisational costs and time. The associated project remuneration will then be undertaken through the co-researchers’ organisations/ employers. If they are independent individuals, then they should be employed and paid appropriately.
* The basis on which people are employed in any project will vary and may include entering into a work contract as an employee of the university, employee of a partner organisation, or as an independent consultant. There may be cases where organisational/institutional constraints will affect the way the co-researchers are remunerated.
* Co-researchers with intellectual disability may require a support worker to undertake their work as co-researchers (e.g. prepare for meetings). Time allowance for a support worker will need to be included in a budget.

## Conducting a Research Project

When conducting a research project we suggest attention to five key areas:

1. Planning and Running Meetings
2. Providing Training
3. Navigating Ethics
4. Joint Ownership of Key Decisions
5. Ongoing Support for the Team

### 1. Planning and Running Meetings

Team meetings are a time when a sense of shared ownership and responsibility is established. It is important to create opportunities where everyone can voice opinions, ask questions, provide feedback, find out about progress and future plans, and observe how decisions are implemented.[[22]](#footnote-22)

### When planning and running meetings, it is important to consider:[[23]](#footnote-23)

* **Frequency.** Take into account people’s other commitments, and fluctuating demands of the project.
* **Location.** Ensure physical access, and ease of access. Is the venue close to public transport? Is there parking on site? Are there accessible toilets near the meeting room? Would remote conferencing via online video or telephone be more appropriate?
* **Agenda and Meeting Materials.** Share documents well in advance of meetings and ask for input from all team members; provide documents in forms that are accessible to all participants (e.g. format accessible to screen readers, in Easy Read). Allow sufficient time for co-researchers with disability to work with a support worker to understand the content and formulate opinions prior to meetings.
* **General Communications Within the Team.** Make sure that all forms of communication are appropriate and accessible. For example, when planning meetings or research-related activities, it is important to remember that, for example, doodle polls are inaccessible to screen readers.
* **Facilitation and Chairing.** Who will lead the meeting? How will they make sure that everyone has the opportunity to have a say? Ensure that all participants’ accessibility needs are known and accommodated in the meeting.
* **Minute Taking and Sharing.** Minutes are an essential way of keeping a record of different people’s contributions, and how they are being put into action. Who will take the minutes? What form will these minutes be in (are they accessible to everyone)? How will they be distributed?

### 2. Providing Training

Training in research skills is important for both co-researchers with disability and academic researchers alike. Training in research co-production can help establish a shared understanding for all involved. Co-production manuals could be developed to guide specific projects.

Learning about research methods can be a valued outcome for co-researchers with disability. It can also be an important step in ensuring that everyone has a say in the research design and implementation and can address the ‘power imbalance’ between academic researchers and co-researchers with disability.[[24]](#footnote-24)

### 3. Navigating Ethics

Most research projects will need to be reviewed by an institution’s ethical review body. Research ethics consider important things like risk and benefit for participants, and consent. Ethics review panels are generally not familiar with the co-production approach to research. Ethics and governance requirements can pose a barrier to the co-production process, for example by questioning the capacity, vulnerability and/or objectivity of co-researchers with disability.[[25]](#footnote-25)

Some of the ethical principles that apply to research participants may also apply to co-researchers with disability. Ethics committees may be unfamiliar with co-production processes that include people with disability as co-researchers, and may consider co-researchers with disability as especially vulnerable. Thus, researchers and co-researchers may need to be prepared to provide additional information on co-production processes as part of their application for ethics approval.

### 4. Joint Ownership of Key Decisions

Not everyone in a co-production project needs to be involved in every decision that is made. What is important is that the collective has a say in who will decide what, and when. Delegating roles and having very clear expectations about who is responsible for which elements of a project is part of this process. The team needs to establish the key decisions in the project and how all co-producers can have input.

### 5. Ongoing Support for the Team

It is important to consider different forms of support for inclusive research teams:

* emotional support (e.g. access to de-briefing, mentoring or peer support);
* practical support (e.g. assistance with travel arrangements or managing out of pocket expenses); and
* research support (e.g. training and supervision in research practices).[[26]](#footnote-26)

Co-researchers with disability may be supported by academic researchers and/or support workers, for example to lead, to be experts by experience, or at a more practical level with transport or understanding jargon. On the other hand, academic researchers may be supported by co-researchers with disability who provide important insights, access to networks, and help with making research accessible.[[27]](#footnote-27) As co-production is a relatively new approach to research, it may be necessary for academic researchers and co-researchers to advocate together for policy change in instances where policies of universities and funding bodies are not in line with or enabling of co-production processes.

Whilst acknowledging the different ways that people may support each other, in co-production the emphasis is placed on cooperation and interdependence.

### Things to Consider when Working with Co-Researchers:

### What are the best ways to engage the team?

* Build rapport among team members through personal check-ins; provide drinks/snacks and schedule social time into meetings (team-building rituals are important).[[28]](#footnote-28)
* In longer meetings, plan for regular breaks and make a space for time out.
* Check in with people about how they want to be referred to in any reports or in meetings.[[29]](#footnote-29)
* It’s crucial that people feel supported to participate and be included. Different individuals will have specific support requirements: find out what they are and make suitable adjustments to the process and content.

Continuous reflection on the process of working together can be a source of ‘data’ about how co-production works.[[30]](#footnote-30) Team meetings focused on reflective discussion about the research and co-production process or reflective diaries are examples of gathering this kind of information.

### How do I keep the team safe?

* It is important to ensure that people involved in co-production do so on a voluntary basis and understand that they can withdraw at any time.[[31]](#footnote-31)
* Power imbalances within a research project can create instances of potential coercion. For example, when a service provider is involved in a research project, service users might not always be free to leave that service and participation in the project might increase vulnerability.
* It’s also important that any risks resulting from the co-production process are managed and openly discussed. For example, a clear plan should be in place that describes how to respond to the potential conflict of interest or emotional distress of team members.[[32]](#footnote-32)
* Co-researchers with a lived experience of disability may find their lived experience both an asset and a potential challenge, particularly if conducting interviews or other forms of primary research with their peers. Self-disclosure is one issue they may need to consider. Clear guidelines can support co-researchers with disability to decide when and how much to disclose; and to reflect on appropriate boundaries.[[33]](#footnote-33)

## Evaluating the Impact of a Research Project

The impact of co-production in research can be understood on two levels. For one, the process of co-production itself can have intrinsic value for those involved, and its ethos of power-sharing and collective control can have a ripple effect that impacts the culture of organisations and institutions. The process can also have an impact on the outcomes of research – for example, increasing relevance and reach.[[34]](#footnote-34)

It takes extra time and resources to do co-production: assessing impact is therefore an imperative if co-production is to be justified to funding bodies and policy makers. Assessment of impact is also important to improve how co-production is understood, carried out and evaluated.[[35]](#footnote-35)

# Evidence Base

Alford, J. (2014). The multiple facets of co-production: Building on the work of Elinor Ostrom. Public Management Review, 16(3), 299–316. https://doi.org/10.1080/14719037.2013.806578

Allen, K., Needham, C., Hall, K., & Tanner, D. (2019). Participatory research meets validated outcome measures: Tensions in the co-production of social care evaluation. Social Policy and Administration, 53(2), 311–325. https://doi.org/10.1111/spol.12468

Beebeejaun, Y., Durose, C., Rees, J., Richardson, J., & Richardson, L. (2014). ‘Beyond text’: Exploring ethos and method in co-producing research with communities. Community Development Journal, 49(1), 37–53. https://doi.org/10.1093/cdj/bst008

Bevir, M., Needham, C., & Waring, J. (2019). Inside co-production: Ruling, resistance, and practice. Social Policy and Administration, 53(2), 197–202. https://doi.org/10.1111/spol.12483

Clarke, J., Waring, J., & Timmons, S. (2019). The challenge of inclusive coproduction: The importance of situated rituals and emotional inclusivity in the coproduction of health research projects. Social Policy and Administration, 53(2), 233-248. https://doi.org/10.1111/spol.12459

Cooke, J., Langley, J., Wolstenholme, D., & Hampshaw, S. (2016). ‘Seeing’ the difference: The importance of visibility and action as a mark of ‘authenticity’ in co-production; Comment on ‘Collaboration and co-production of knowledge in healthcare: Opportunities and challenges’. International Journal of Health Policy and Management, 6(6), 345–348. https://doi.org/10.15171/ijhpm.2016.136

Crompton, A. (2019). Inside co-production: Stakeholder meaning and situated practice. Social Policy and Administration, 53(2), 219-232. https://doi.org/10.1111/spol.12466

Durose, C., Needham, C., Mangan, C., & Rees, J. (2017). Generating ‘good enough’ evidence for co-production. Evidence & Policy, 13(1), 135–151. https://doi.org/10.1332/174426415X14440619792955

Fisher, P. (2016). Co-production: What is it and where do we begin? Journal of Psychiatric and Mental Health Nursing, 23(6-7), 345-346. http://doi.org/10.1111/jpm.12281

Flinders, M., Wood, M., & Cunningham, M. (2016). The politics of co-production: Risks, limits and pollution. Evidence & Policy, 12(2), 261–279. https://doi.org/10.1332/174426415X14412037949967

Frankena, T. K., Naaldenberg, J., Bekkema, N., van Schrojenstein Lantman-de Valk, H. J. M., Cardol, M., & Leusink, G. (2018). An exploration of the participation of people with intellectual disabilities in research – a structured interview survey. Journal of Applied Research in Intellectual Disabilities, 31(5), 942-947. http://dx.doi.org/10.1111/jar.12453

Jung, T., Harrow, J., & Pharoah, C. (2012). Co-producing research: Working together or falling apart? CGAP briefing note 8. Retrieved from http://www.cgap.org.uk/uploads/Briefing Papers/CGAP Briefing Note 8 – Co-producing research.pdf

Matthews, R., & Papoulias, C. (2019). Toward co-productive learning? The exchange network as experimental space. Frontiers in Sociology, 4. https://doi.org/10.3389/fsoc.2019.00036

Nind, M., & Vinha, H. (2012). Doing research inclusively, doing research well? Report of the study: Quality and capacity in inclusive research with people with learning disabilities. Retrieved from https://www.southampton.ac.uk/assets/imported/transforms/content-block/UsefulDownloads\_Download/97706C004C4F4E68A8B54DB90EE0977D/full\_report\_doing\_research.pdf

Nind, M., & Vinha, H. (2013). Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers. Retrieved from http://eprints.ncrm.ac.uk/3187/1/Nind\_practical\_considerations\_in\_doing\_research\_inclusively.pdf

Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. British Journal of Learning Disabilities, 42(2), 102-109. https://doi.org/10.1111/bld.12013

Rycroft-Malone, J. (2014). From knowing to doing: From the academy to practice; Comment on ‘The many meanings of evidence: Implications for the translational science agenda in healthcare’. International Journal of Health Policy and Management, 2(1), 45-46. https://doi.org/10.15171/ijhpm.2014.08

Rycroft-Malone, J., Burton, C. R., Bucknall, T., Graham, I. D., Hutchinson, A. M., & Stacey, D. (2016). Collaboration and co-production of knowledge in healthcare: Opportunities and challenges. International Journal of Health Policy and Management, 5(4), 221–223. https://doi.org/10.15171/ijhpm.2016.08

Staley, K. (2015). ‘Is it worth doing?’ Measuring the impact of patient and public involvement in research. Research Involvement and Engagement, 1(1), 6. https://doi.org/10.1186/s40900-015-0008-5

Walmsley, J., Strnadová, I., & Johnson, K. (2018). The added value of inclusive research. Journal of Applied Research in Intellectual Disabilities, 31(5), 751-759. https://doi.org/10.1111/jar.12431

Verschuere, B., Brandsen, T., & Pestoff, V. (2012). Co-production: The state of the art in research and the future agenda. VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations. 1083-1101. <https://doi.org/10.1007/s11266-012-9307-8>

# Suggested Resources

Amadea, T., Boylan, A.-M., & Locock, L. (2016). A researcher’s guide to patient and public involvement: A guide based on the experiences of health and medical researchers, patients and members of the public. Retrieved from https://oxfordbrc.nihr.ac.uk/wp-content/uploads/2017/03/A-Researchers-Guide-to-PPI.pdf

Agnew, L., Ali, Y., Ballentine, S., Canser, M., Connor, J., Jones, R., . . . Corrigan, P. (2016). Inspiring change manual: A community-based participatory research manual for involving African Americans with serious mental illness in research. Retrieved from https://www.pcori.org/sites/default/files/IIT-Inspiring-Change-CBPR-Manual.pdf

Community Mental Health Drug and Alcohol Research Network (2015). Ask the experts: A CMHDARN best practice guide to enabling consumer and carer leadership in research and evaluation. Retrieved from https://cmhdaresearchnetwork.com.au/wp-content/uploads/2016/11/BPG-CCPIR-FINAL-201512011.pdf

Cooperative Research Centre for Living with Autism (2016). Inclusive research practice guides and checklists for autism research: Version 2. Retrieved from https://www.autismcrc.com.au/sites/default/files/inline-files/Inclusive%20research%20practice%20guides%20and%20checklists%20-%20FInal%20report.pdf

Farmer, M., & Macleod, F. (2011). Involving disabled people in social research: Guidance by the Office for Disability Issues, UK. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/321254/involving-disabled-people-in-social-research.pdf

Garcia Iriarte, E., & O’Doherty, S. (2010a). Inclusive research network, Ireland co-researcher handbook: Relationships and supports study. Retrieved from http://www.fedvol.ie/\_fileupload/Inclusive Research Network/IRN Relationships and supports Co-Researcher handbook 04 June 2010.pdf

Garcia Iriarte, E., & O’Doherty, S. (2010b). Inclusive research network, Ireland supporter handbook: Relationships and supports study. Retrieved from http://www.fedvol.ie/\_fileupload/Inclusive Research Network/IRN Relationships and supports Supporter handbook 04 June 2010.pdf

Hancock, N., Bundy, A., Waghorn, G., & Pioneer Clubhouse, Sydney (2013a). Demystifying research: Training modules designed to empower mental health consumers to engage more fully in research (TRAINEE VERSION). In: The University of Sydney; Schizophrenia Fellowship of NSW Inc.; Pioneer Clubhouse (Consumer Research Team); Queensland Centre for Mental Health Research. Retrieved from https://ses.library.usyd.edu.au/handle/2123/9318

Hancock, N., Bundy, A., Waghorn, G., & Pioneer Clubhouse, Sydney (2013b). Demystifying research: Training modules designed to empower mental health consumers to engage more fully in research (TRAINER VERSION). In: The University of Sydney; Schizophrenia Fellowship of NSW Inc.; Pioneer Clubhouse (Consumer Research Team); Queensland Centre for Mental Health Research. Retrieved from https://ses.library.usyd.edu.au/handle/2123/9319

Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., . . . Turner, K. (2018). Guidance on co-producing a research project. Retrieved from Southampton: https://www.invo.org.uk/wp-content/uploads/2019/04/Copro\_Guidance\_Feb19.pdf

Inclusive Research Network (2018). How we work: The inclusive research network’s way of doing projects. Retrieved from http://www.fedvol.ie/\_fileupload/Inclusive%20Research%20Network/IRN%20How%20we%20work.pdf

National Health and Medical Research Council (2016). Statement on consumer and community involvement in health and medical research. Retrieved from https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research

Roper, C., Grey, F., & Cadogan, E. (2018). Co-production: Putting principles into practice in mental health contexts. Retrieved from https://static1.squarespace.com/static/5b6a7f7e71069901ea5ef1eb/t/5bda51b70ebbe8a5aa1cd5ad/1541034454031/Coproduction putting-principles-into-practice+%281%29.pdf

Smith-Merry, J. (2017). Research to action guide on inclusive research. Retrieved from https://www.cadr.org.au/research-to-action-guides/inclusive-research

Social Care Institute for Excellence (2015). Co-production in social care: What it is and how to do it. Retrieved from https://www.scie.org.uk/publications/guides/guide51/

# Appendix A

### Co-Produced Research: Budget Template

|  |  |  |  |
| --- | --- | --- | --- |
| Co-Researcher Compensation | Estimated | Actual | Notes |
| Co-Researcher 1 |  |  | E.g. Casual employment at rate X, for N hours |
| Co-Researcher 2 |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
| Total |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| Meeting Expenses | Estimated | Actual | Notes |
| Venue Hire |  |  |  |
| Catering |  |  |
| Travel and Accommodation for Attendees |  |  |
| Printing and Other Supplies |  |  |
| Total |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| Research Expenses | Estimated | Actual | Notes |
| Research Assistant |  |  |  |
| Payments to Participants |  |  |
| Total |  |  |

# Appendix B

### Project Information Template

|  |  |
| --- | --- |
| **Project Title:** |  |
| **Project Description:** | This co-produced research project aims to address… |
| **About Your Role:** | As a co-researcher you will be involved in… |
| **Training and Support:** | We value your expertise across all stages of the research, and will support you to access the information and tools you need to complete the project through… |
| **Approximate Time Commitment:** | X hours, over N months |
| **Meeting Information:** | Dates/times:  Location: |
| **Salary:** |  |
| **Out-of-pocket Expenses Associated with the Role of Researcher/Co-Researcher:** |  |
| **Contact Information for Project Leaders:** | Lead 1:  Lead 2: |

## For more information and further resources visit:

## [www.disabilityinnovation.unsw.edu.au](http://www.disabilityinnovation.unsw.edu.au)



1. Walmsley, Strnadová, & Johnson, 2018. [↑](#footnote-ref-1)
2. Durose, Needham, Mangan, & Rees, 2017, p. 135. [↑](#footnote-ref-2)
3. Ryecroft-Malone, Burton, Bucknall, Graham, Hutchinson, & Stacey, 2016. [↑](#footnote-ref-3)
4. The Disability Innovation Institute held a workshop on co-production in disability research at UNSW Sydney on 12 November 2019, which also informed these Guidelines. At this workshop representatives of Australia’s leading disabled people’s organisations and disability representative organisations, offered alternative terms to ‘power-sharing’, such as ‘power-taking’ and ‘power-making’, which they suggested as more appropriate. Since ‘power-sharing’ is more widely understood and used within the literature, we felt that more discussion is needed before a generally approved alternative can be used. In these Guidelines we have therefore continued to use power-sharing. [↑](#footnote-ref-4)
5. Fisher, 2016. [↑](#footnote-ref-5)
6. See for example Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016; Amadea, Boylan & Locock, 2016; Frankena, Naaldenberg, Bekkema, Schrojenstein Lantman-de Valk, Cardol & Leusin, 2018; Nind & Vinha, 2012. [↑](#footnote-ref-6)
7. Community Mental Health Drug and Alcohol Research Network, 2015. [↑](#footnote-ref-7)
8. Amadea, Boylan & Locock, 2016. [↑](#footnote-ref-8)
9. Frankena, Naaldenberg, Bekkema, Schrojenstein Lantman-de Valk, Cardol & Leusin, 2018; Nind & Vinha, 2012. [↑](#footnote-ref-9)
10. Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016. [↑](#footnote-ref-10)
11. Nind & Vinha, 2012. [↑](#footnote-ref-11)
12. National Health and Medical Research Council, 2016. [↑](#footnote-ref-12)
13. Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018. [↑](#footnote-ref-13)
14. Nind & Vinha, 2014. [↑](#footnote-ref-14)
15. Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018. [↑](#footnote-ref-15)
16. Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016. [↑](#footnote-ref-16)
17. Community Mental Health Drug and Alcohol Research Network, 2015; Farmer & Macleod, 2011. [↑](#footnote-ref-17)
18. Roper, Grey & Cadogan, 2018. [↑](#footnote-ref-18)
19. Community Mental Health Drug and Alcohol Research Network, 2015. [↑](#footnote-ref-19)
20. Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018. [↑](#footnote-ref-20)
21. Amadea, Boylan & Locock, 2016. [↑](#footnote-ref-21)
22. Matthews & Papoulias, 2019. [↑](#footnote-ref-22)
23. Note: These points have been adapted from a number of other helpful guidances, some relating to specific groups such as people with lived experience of mental health issues and people on the autism spectrum (Agnew, Ali, Ballentine, Canser, Connor, Jones, Laster, Muhammad, Noble, Sheehan, Smith & Walley, 2016; Amadea, Boylan & Locock 2016; Community Mental Health Drug and Alcohol Research Network, 2015; Cooperative Research Centre for Living with Autism, 2016). [↑](#footnote-ref-23)
24. Amadea, Boylan & Locock 2016, 2016. [↑](#footnote-ref-24)
25. Nind & Vinha, 2012; Smith-Merry, 2017. [↑](#footnote-ref-25)
26. Community Mental Health Drug and Alcohol Research Network, 2015. [↑](#footnote-ref-26)
27. Nind & Vinha, 2014. [↑](#footnote-ref-27)
28. Clarke, Waring & Timmons, 2019; Crompton, 2019. [↑](#footnote-ref-28)
29. Inclusive Research Network, 2018; Nind & Vinha, 2013. [↑](#footnote-ref-29)
30. Hickey, Brearley, Coldham, Denegri, Green, Staniszewska, Tembo, Torok & Turner, 2018. [↑](#footnote-ref-30)
31. Community Mental Health Drug and Alcohol Research Network, 2015. [↑](#footnote-ref-31)
32. Community Mental Health Drug and Alcohol Research Network, 2015. [↑](#footnote-ref-32)
33. Community Mental Health Drug and Alcohol Research Network, 2015. [↑](#footnote-ref-33)
34. Staley, 2015. [↑](#footnote-ref-34)
35. Staley, 2015. [↑](#footnote-ref-35)