



CO-PRODUCTION KICKSTARTER

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A short guide to get started,
and become more familiar with
co-production research

Co-production Kickstarter

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Note: for terminology used in this tool see [p.11](#)

Acknowledgments

Co-production Kickstarter was conceptualised by **Community Mental Health Drug and Alcohol Research Network (CMHDARN)** and developed in partnership with Lived Experience researchers **Brett Bellingham**, University of Sydney, **Bradley Foxlewin**, Consumer Led Research Network (CLRN), University of Sydney, University of Technology Sydney (UTS), and **Dr Grenville Rose**, CLRN University of Sydney, and Conventional academic researcher, **Dr Jo River**, Faculty of Health, UTS.

The Kickstarter was co-produced in response to a need for a resource to support meaningful co-production research in the mental health and alcohol and other drugs sectors, and thereby promote greater participation of lived experience in community-based, health, and academic research practice.

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CO-PRODUCTION KICKSTARTER

Co-production research as distinct from co-design research

The Kickstarter provides a guide to co-production research that is consistent with original conceptualisations of co-production and aligns with long-held advocacy efforts from people with lived experience. Co-production research is distinct from co-design research, it is conceptualised as a *continuous partnership* between people with lived experience and conventional mental health and alcohol and other drug researchers, who work together through *all stages* of the research process. This includes planning, designing, conducting, and disseminating research. The Kickstarter also discusses a form of co-design that shares many elements of co-production but has important differences. In co-design, partnership between people with lived experience and conventional researchers is not guaranteed to be continuous and may occur during *any OR all stages* of the research process.

This resource is for people who have an interest in deepening participation and co-producing research in 'mental health' and 'alcohol and other drugs', including:

- People with lived/living experience of mental health challenges, trauma, distress, extreme states, and/or suicidal crisis (people with lived experience - often identified as consumers/service users)
- People who use or have used substances
- People who undertake 'mental health' and/or 'alcohol and other drug' research, including Lived Experience, Peer and Conventional researchers.
- People who support people who use substances and/or people with a lived experience and may identify as carers, friends, supporters, significant others, family members, or support workers
- People within organisations, agencies, services, and communities of people who are interested in actively supporting co-production, lived experience and peer leadership in research.

In this document, for brevity, people with lived experience of mental health and/or substance use are respectfully referred to as people with lived experience. The terms Lived Experience researcher and Peer researcher are used to refer to people with a lived experience of mental health challenges or people who use substances who are in identified Lived Experience or Peer researcher roles. The term Conventional researcher is used to refer to people who undertake mental health or alcohol and other drug (AOD) research, who are not in an identified Lived Experience or Peer research role, and who hold other positions within organisations including as clinicians, practitioners, academics, or professional researchers.

The co-production landscape

Within Australia and internationally, agencies and organisations are calling for greater levels of partnership at all stages of the research process to ensure that community and health services, as well as academia, are relevant and responsive to people with lived experience, people who use substances, carers, and families and supporters.^{1,2}

CO-PRODUCTION KICKSTARTER

Similar words, different meanings

'Participatory research' describes ways of doing research that include involvement of or partnership with people who are usually the subjects of research.

Participatory approaches may have different names, which can be confusing, including (but not limited to) co-production, co-design, co-inquiry, co-construction, 'personal and public involvement' (PPI), and participatory action research. People may use these terms interchangeably, and some do share common elements. However, they refer to approaches with different histories and influences. For example, co-design originated from Scandinavian product development initiatives with end-users, whereas co-production emerged from the work of civil rights and social care movements, although these approaches have also been influenced by each other and social movements.^{3,4}

In this tool, we highlight the approach called 'co-production', which was influenced by the work of political scientist, Eleanor Ostrom, who demonstrated that involvement of citizens in service development led to sustainable and equitable services, and civil rights law scholar, Edgar Cahn, who conceptualised co-production as a process of creating a more democratic and just society.^{4,5}

Co-production in mental health and alcohol and other drugs research

Co-production in this context refers to a process where people with lived experience of mental health and/or substance use are co-researchers employed as Lived Experience or Peer researchers, and who share decision-making power throughout all stages of the research process - including sharing the results of the research study. This way of doing research promotes the inclusion of those people who have been historically excluded and thereby stigmatised in research and 'knowledge production'; and improves the relevance and resonance of research priorities, outcomes and raising the quality of research interpretation and knowledge translation.^{6,7}

Words have power, effects and histories

In the past, people with lived experience had little power to influence how words were used to describe them and their experiences, and how people were consequently conceptualised. The collective efforts and activism of people with lived experience and their supporters has brought about change, as exemplified by this tool, which was co-produced by Lived Experience, Peer, and Conventional researchers, and uses people-first language. However, people and communities may use other terms to describe their identity and experiences. We recommend that all teams working to co-produce research develop a 'project lexicon' (a list of words that the team will use to refer to people and their experiences, including culturally specific terms and pronouns) that prioritise Lived Experience and Peer research partners' perspectives on language. We also recommend connecting with and considering the language used by existing organisations and Lived Experience groups (e.g., NADA, 2019, Language Matters, and MHCC 2018 Recovery Oriented Language Guide^{8,9}).

Co-production research and levels of participation

Sherry Arnstein (1969) described levels of citizen participation in organisations and institutions, arguing that they range from 'non-participation' to 'tokenism' to genuine partnership and citizen leadership.¹⁰ Similarly, there are levels of participation in research ranging from lower levels of **'non-participation'**, where people with lived experience are excluded, or research is **'done to'** them or they are participants or subjects in a project; to mid-level participation where people with lived experience are heard but have little influence over the research, which is to say it is **'done for'** lived experience populations; and top-level participation of genuine partnership and leadership, where research is **'done with'** or **'done by'** people with lived experience.

Doing **BY****Led & owned
by Lived
Experience
and/or Peer
Researchers**

- Lived Experience and/or Peer researchers own and lead the research study, leading continuously through all stages of planning, design, delivery and dissemination.
- Lived Experience and Peer researchers are the experts and may collaborate with Conventional researchers who provide input and resources to support Lived Experience and/or Peer researchers, who often address critical issues relevant to community needs.
- Lived Experience and/or Peer led research is often integrated into and responsive to affected communities and has governance structures that further engage additional people with lived experience, via steering, reference, or advisory groups.

Doing **WITH****Co-production**

- Lived Experience and/or Peer researchers have experiences relevant to the study and are employed to work in continuous partnership with Conventional researchers in all stages of the research, including planning, designing, conducting, and disseminating research.
- Ownership of the project and research is shared, power differentials are acknowledged, negotiated, and addressed.
- The number of Lived Experience/Peer and Conventional researcher numbers are at least equal, or Lived Experience/Peer researchers form the majority. Expertise is equally valued, but Lived Experience/Peer perspectives are privileged in discussions.

Co-design

- Lived Experience and/or Peer researchers have experience relevant to the area of study, and work in partnership with Conventional researchers in any or all stages of the research, including planning, designing, conducting, and disseminating research.
- Numbers of Lived Experience/Peer researchers and Conventional researchers are at least equal, or Lived Experience/Peer researchers form the majority. Lived Experience/Peer researcher perspectives are privileged, power differentials are addressed.
- Expertise is equally valued, but Lived Experience/Peer perspectives are privileged in discussions.

Doing **FOR****Reference Group
or Advisory Group**

- A group of people with lived experience relevant to the area of study, are consulted at least once, but typically multiple times, to gain advice on a research area or design.
- They may or may not be considered as researchers and may have limited power to influence the research design and conduct.
- Ongoing input is not guaranteed, but typically will happen during active stages of research project. The Conventional researcher is the expert and owner of the project and research.

Consultation

- One or more person/s with lived experience are consulted at least once for input that may or may not impact on the design. The experience of this person or group may or may not be specific to the area or study.
- The person or group may or may not be considered as a researcher/s and may have limited-to-no power to influence the research design or conduct. Ongoing input is not guaranteed.
- The Conventional researcher is the expert and owner of the project and research.

Doing **TO****Subject /
Participation**

- People with lived experience have no power over the research design or process.
- Conventional researchers gather data on people with lived experience as: subjects where quantitative data is collected about the person or data is collected by pre-set survey questions; or as participants where qualitative data is collected, and responses may influence subsequent questions or observations.
- Conventional researchers are the experts and owners of the project and research.

Exclude

**Coercion
Manipulation
Exclusion**

- People with lived experience are excluded from research or studied by Conventional researchers without consent e.g., big data analytics or covert studies of human behaviour.
- The Conventional researcher is the expert and does not seek participation.

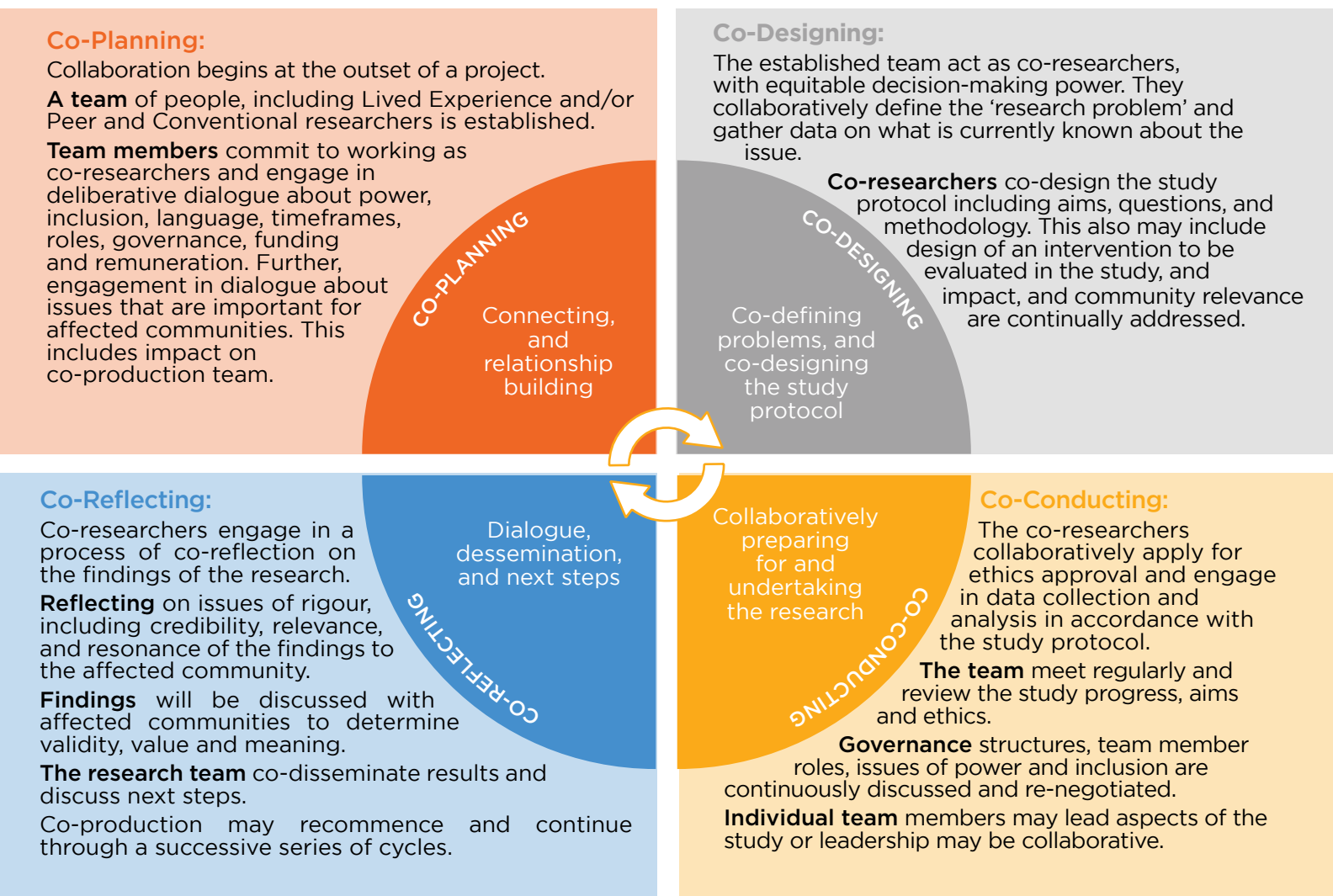
CO-PRODUCTION IS AN ASPIRATION AND AN APPROACH

Co-production research is an aspiration - It is a way of doing research that is intentionally democratic and aspires to being emancipatory. It actively inverts traditional ways of working by centring the perspectives and wisdom of people and communities who are impacted by an experience, event, or circumstances rather than the perspectives of Conventional researchers. In co-production research, teams work in partnership, sharing power, and building each other's capacity to co-produce new ways of responding to, and understanding, lived experiences of mental health challenges, trauma, distress and/or substance use.

The co-production research team shares an understanding that, to meet the needs of affected communities, the perspectives of people with lived experience must be elevated or privileged. Positive discrimination in co-produced research is necessarily disruptive to promote new ways of knowing and doing.^{12,13}

Co-production research is an approach - Co-production does not suggest a particular research methodology - although elevating lived experience perspectives will no doubt influence the methodology of a study - but it does lay out a way of working where Lived Experience and/or Peer and Conventional researchers come together as co-researchers within a team, sharing power and responsibility for decisions at ALL stages of the co-production research cycle, including choice of research methods.

CO-PRODUCTION RESEARCH CYCLE



CO-PRODUCTION KNOW-HOW

Preparing the Ground

Partners not participants - In co-production, people with lived experience are colleagues and co-researchers NOT participants⁴, including Lived Experience, Peer or Conventional researchers (unless the team choose to use methodologies such as autoethnography). Teams do not need ethics approval for the involvement of any research partners, including Lived Experience, Peer, or Conventional researchers.

However, co-production research teams of Lived Experience and/or Peer and Conventional researchers may recruit people, including people with lived experience, as participants or subjects for a study, which would require ethics approval. That said, many Lived Experience and Peer researchers reject the current positioning of people with Lived Experience as ‘vulnerable’ subjects or participants. This does not mean that Lived Experience and Peer researchers ignore ethical research practice or participant safety, but instead privilege notions of justice, equity, respect, and right to self-determination.¹⁴

Payment matters - Lived Experience and Peer researchers in co-production teams need to be paid fairly for their work.^{15,16} This involves valuing lived experience skills and expertise, as well as considering budget requirements, and challenging organisational and institutional demands for traditional credentials. When considering fair pay, the team consider how much Conventional researchers are paid for working on the same or similar projects, as well as the skills and experience of Lived Experience and Peer researchers.¹⁷ People with lived experience are paid as employees or contractors, with employment being prioritised where possible, if preferred by the Lived Experience or Peer researcher. Some people with lived experience may prefer other payment methods such as vouchers. However, vouchers should only offered if this is preferred by the Lived Experience or Peer researcher, as opposed to being the preferred method of the organisation. Some Lived Experience or Peer researchers may wish to work as volunteers in service to an affected community. Again, this should only be considered if it is the preferred option of the Lived Experience or Peer researcher.

Supportive organisations and institutions should consider strategies and opportunities for supporting the co-planning stages of co-production research, as well as opportunities for ongoing and secure employment for Lived Experience and Peer researchers. Funding agencies can assist in this endeavour by changing exclusionary criteria such as higher degree credentials and extensive track records, and instead privileging Lived Experience and Peer researcher skills and experience, including experience in co-production.

Considering context - In co-production, the impacts of broader social structures on the research process are carefully considered, for example the impacts of policy and societal values on people with lived experience and issues of stigma and discrimination, as well as criminalisation, that might come with self-disclosure. Also, the team needs to consider the needs of Lived Experience researchers for confidentiality, and take into account the impact of visibility in the research.¹¹

Supportive organisations can also develop language and conduct guides with people with Lived Experience and make these available to researchers. See for example the guides developed by NADA (2019) and MHCC (2018).^{8,9}

CO-PRODUCTION KNOW-HOW

Seeking diversity and disruption - In co-production, research teams are composed of Lived Experience and/or Peer researchers and Conventional researchers with a diversity of relevant experience, knowledge, wisdom, and skills. Authentically engaging with a diversity of perspectives can lead to uncomfortable conversations. These are, however, viewed as a strength as they enable innovation and help ensure relevance of the research to affected communities.^{6,7,18}

During the co-planning stage, the research team should seek advice from a steering/advisory group or affected community on the best make-up of the team to ensure it adequately reflects the diversity of the community in which it is situated. Recruiting processes that support inclusion should also be considered since insistence on formal applications, credentials, and resumes may block access for members of an affected community. For example, steering/advisory and community groups may be able to make recommendations for people to invite to a 'first meeting' or informal chat.

Lived Experience and Peer researchers' diversity can include factors such as relevance of their lived expertise to the project, as well as social background, recency and variations of experience of treatment and care, connection with affected communities and the wider Consumer and Peer movements.¹⁹

Lived Experience and Peer researchers may also bring educational expertise in research. However, this does not privilege education over other important diversity criteria. Relevance and diversity of backgrounds should be the key focus. Conventional researchers' diversity is based on the relevance of their research skills and knowledge, and skills and experience in working collaboratively with people with lived experience. The process of ensuring diversity within the team may be ongoing as the project planning and design of the project emerges.

Methodological mentionables - In co-production, researchers aim for equal and continuous participation through all stages of the research project and collaboration starts early.^{12,20}

Although elevating lived experience perspectives influences the choice of methodology, co-production does not prescribe the research methodology or underlying (explicit or implicit) concepts of a research project. Quantitative research methods and medical/psychiatric conceptualisations of distress and substance use may be privileged in some health research, but co-production teams may consider methodologies that resonate with people with lived experience, or provide more understanding of lived experience perspectives (e.g., qualitative methods), or offer more opportunities for community participation (e.g., cultural ethnography), or other mixed methods.¹²

Co-production teams may also consider different ways of conceptualising and responding to distress and AOD use, including, trauma-informed and harm-minimisation approaches, as well as considering the relationship between distress and substance use and other intersecting social disadvantages such as class, race, gender, sexuality, disability, and poverty etc.

Traditional publications and presentations often arise out of co-production work. However, co-production teams also need to consider research dissemination and translation that is acceptable and accessible to affected communities, such as infographics, zines, podcasts or film etc.^{12,17} Co-production teams might also guard against replicating systemic separation of mental health and AOD services, and recognise that distress, extreme states, and AOD use can be related issues, including the management of distress via substance use.

Doing the Work

Addressing power and attending to relationships - In co-production, conversations about power are explicit.

Teams practice deliberate egalitarianism by considering how power might silence people with lived experience and by working to elevate lived experience perspectives. Also, the voices of Lived Experience and Peer researchers are amplified by ensuring that people with lived experience make up (at least) half of the research team.⁴

Team members build respect and reciprocity through careful attention to power-dynamics and recognition of, and value for, the different kinds of knowledge and expertise each researcher brings.⁵ For a guide on how to navigate discussions about power, see Roper et al. (2018) power exercises.⁴

Time, place, and communication - Co-production is a negotiated process which takes time. Meaningful research that seeks to support change for affected communities is deliberate. Time is often considered a luxury in research circles, but 'slow scholarship' can create a collective ethic of care and integrity that is a counterpoint to escalating and unsustainable demands for speed and productivity implicated in work stress, health problems and burnout for all researchers, and can exclude people with fluctuating capacity.²¹ Co-production research teams may need to challenge organisations and funding agencies that state a commitment to co-production but are focused on speedy deliverables. Organisations and funding agencies can support co-production by providing the time and resources and remaining in dialogue with the co-production research team about the project timeline and deliverables.

Place is also an important consideration. People with lived experience may have had traumatising interactions within healthcare services in some locations, and meeting in these locations may be a barrier to participation.^{12,17} To increase access, consider meeting in community settings that are physically and emotionally accessible such as a local library meeting room that sets the scene for the activity of research. Additionally, Lived Experience and Peer researchers may require reasonable adjustments to the co-production process, such as breaks during longer meetings. To ensure that all team members feel supported and included, discuss the specific requirements of the team members, including the need for rest due to the fatigue of co-production work which is often transgressive to current ways of knowing and doing.

Finally, communication needs to be adapted for the needs of all researchers.¹⁹ Hint: not everyone uses email or has access to a computer or the internet or the technology for meetings. Written and verbal communication can also ensure that people can respond in person or have time to read ideas and respond at their own pace. Accessible communication is a matter of equity in teams with diverse groups of people. Work out what works, what needs to be communicated, and how often.

Learning by doing - It's important to get started. Start at the best level you can achieve right now. Indigo Daya (2020) has noted that it's good to increase participation of people with lived experience in research, but "it's even more important to be honest about where you are".²² Indigo Daya provides a checklist to assess the participation possibilities for a project if the team is unsure (see list of resources).²²

Aspire don't settle. Even if you can't do co-production right now, seeking external training and support in co-production approaches can help build the capacity of the whole team for future projects.

Don't rush. Remember, relationships are central and (as tempting as it may be) don't skip the conversations about power, diversity, and inclusion.

WANT MORE CO-PRO KNOW HOW?

A BOOKLET ON CO-PRODUCTION



Cath Roper, Flick Grey and Emma Cadogan (2018) Co-production: Putting Principles into Practice in Mental Health Contexts. (Australian Free and available online). This booklet provides a detailed overview of the principles, practices and challenges of co-production and how to have conversations about power. It includes some case study examples.

CO-PRODUCTION CHECKLISTS



Indigo Daya (2020). The Participation Ladder: A Consumer/Survivor Lens. (Australian Free and Available online). Do the check-list to determine the level of participation you are working at and consider how you might reach a higher level of participation. Includes some great tips on good practice in co-production.

A BOOK ON CO-DESIGN



Kelly Ann McKercher (2020). Beyond sticky notes. Sydney, Australia: www.beyondstickynotes.com Discusses a form of co-design that shares many elements of co-production. The book provides details about methods and processes.

HOW TO CREATE DIVERSITY IN PARTICIPATORY RESEARCH TEAMS



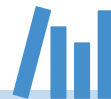
Indigo Daya, Birdget Hamilton and Cath Roper (2020). Authentic engagement: A conceptual model fo welcoming diverse and challenging consumer and survivor views in mental health research, policy and practice. *International Journal of Mental Health Nursing*, 29, 299-311. doi: 10.1111/inm.12653. Outlines the multiple experiences and perspectives of people with LE and how these can be bought into research processes.

EMPLOYMENT AND PAY IN PARTICIPATORY RESEARCH



Kinnon MacKinnon and colleagues (2021). The political economy of peer research: Mapping the possibilities and precarities of paying people for lived experience. *British Journal of Social Work*. doi: 10.1093/bjsw/bcaa241 This paper looks at issues of working conditions and pay for LE and peer researchers.

ETHICAL CONSIDERATIONS IN CO-PRODUCTION



Yasmine Beebeejaun and colleagues (2013). Public harm or public value? Towards co-production in research with communities. *Environment and Planning C: Government and Policy*, 31. doi:10.1068/c12116 This paper considers key ethical issues and how we might re-think the relationship between the researcher and the 'researched'.

INSTITUTIONAL BARRIERS AND ENABLERS TO CO-PRODUCTION



Jonathan Paylor and Christopher McKeivitt (2019). The possibilities and limits of "co-producing" research. *Perspective*, 4(23): doi: 10.3389/fsoc.2019.00023 This paper examines how collaboration can become tokenistic and reproduce power imbalances. Supports researchers to understand the barriers and enablers of co-production.

PARTICIPATORY RESEARCH AS A MATTER OF JUSTICE



Stephanie Leblanc and Elizabeth Kinsella (2006). Towards epistemic justice: A critically reflexive examination of 'sanism' and implications for knowledge generation. *Studies in Social Justice*, 10(1), 59-78. doi:10.26522/ssj.v10i1.1324 This paper looks at issues of stigma and discrimination in research and how this might be challenged through social and epistemic justice principles.

EXAMPLE OF LIVED EXPERIENCE LED RESEARCH



Bradley Foxlewin (2012). What is happening at the seclusion review that makes a difference? A consumer led research study. This study is an example of lived experience led research that addresses critical issues relevant to community needs.

TERMINOLOGY USED IN THIS TOOL

Lived experience

The first hand (and collective) experiences, wisdom, and expertise of people who use substances and people who experience (or have experienced) mental health challenges, trauma, distress, extreme states, and/or suicidal crisis. We acknowledge that, while this term has been used in the 'mental health' field, it has not been commonly used for people who use substances. We have chosen to use it here to refer to people from both 'groups' for brevity and because it is the standpoint from which these groups make their knowledge claims.

Co-production research team

A research team comprised of people with lived experience and/or people who use substances and Conventional researchers who are working together as colleagues and co-researchers on a research project.

Support people/networks

People who offer support or services to people with lived experience and people who use substances and may identify as carers, friends, supporters, significant others and/or family members, including family of origin and chosen family, or support workers.

Lived Experience researcher

People with a lived experience who are in an identified role, and engage in research within the community, organisations, institutions and/or services. The researcher may or may not identify or be referred to as a Lived Experience researcher and may use other titles.

Peer researcher

People who have lived experience of mental health conditions or use or have used substances who are in an identified role, and engage in research within the community, organisations and/or services. The researcher may or may not identify or be referred to as a Peer researcher and may use other titles.

Conventional researcher

People who do mental health and AOD research within organisations, institutions, and/or services, including clinicians, other practitioners, academics, and professional researchers. Conventional researchers are drawing on educational expertise as opposed to lived experience.

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