CO-PLANNING

CO-DEFINING

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CO-DESIGN KICKSTARTER

CO-DESIGN
KICKSTARTER

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

CO-DESIGN KICKSTARTER

Published by **Community Mental Health Drug and Alcohol Research Network**

Acknowledgments

CO-DESIGN KICKSTARTER

The Co-design Kickstarter provides a guide to the co-design of research (co-design research) that draws on the multiple lineages of co-design and the knowledge(s) of people with lived and living (lived/living) experience. The Co-design Kickstarter conceptualises co-designed research as distinct from co-produced research. In the mental health, alcohol and other drug (MHAOD) sectors, co-design research has sometimes been positioned as a lower level of participation than co-production research (Happell et al., 2019, p.50). However, co-design research might be better understood as distinct from co-production in that it describes a *continuum* of participation.

At its most participatory, co-design research involves people with lived/living experience and conventional MHAOD researchers (conventional researchers) working together through *all stages* of the research cycle and may be nearly indistinguishable from co-production research. At lower levels of participation, co-design research, may involve people with lived/living/living experience working together with conventional researchers in one or more *key stages* of the research cycle.

This Kickstarter outlines two approaches to co-design research

First is a **'Substantive' co-design research** approach that aligns with calls from social and human rights movements, including Consumer/Survivor, Peer, and Disability movements (lived experience community) that have advocated for re-balancing and restoration of power in the production of knowledge. Substantive co-design research involves active partnership between people with lived/living experience and conventional researchers through all stages of co-planning the research, co-defining the research design, co-conducting, and co-disseminating the research.

The Co-design Kickstarter also discusses a **'Bare Minimum' co-design research** approach that meets the lived experience community's minimum expectations for co-design research to align with Consumer/Survivor, Peer and Disability movement advocacy efforts. This approach involves people with lived/living experience working together with conventional researchers in *key stages* of the research cycle, including co-deciding the research design, co-deciding any deviations in the research design during the life of the project, co-interpreting data, and transparent reporting on limitations of this level of co-design.

WHO IS THIS RESOURCE FOR

This resource is for people who have an interest in deepening participation and co-designing 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, who may identify as consumers/service users

- People who use or have used substances, including alcohol and other drugs (people who use substances)

- People who undertake 'mental health' and/or 'alcohol and other drug' research (MHAOD), including Lived Experience, Peer and conventional researchers

- People who support people with lived/living experience or people who use substances and/or people who identify as carers, friends, kin, supporters, significant others, family members, or support workers

- People within organisations, agencies, services, and communities who are interested in actively supporting co-design, lived experience and peer leadership in research

A NOTE ON LANGUAGE

In this document, for brevity, people with lived/living experience of mental health challenges and people who use substances are respectfully referred to as **people with lived/living experience.** The terms Lived Experience researcher and Peer researcher are used to refer to people who use their knowledge and wisdom gained through the lived/living experience of mental health challenges and/or substance use, and are employed in a Lived Experience or Peer researcher role that involve active, open, and intentional use of this knowledge and wisdom.

The term conventional researcher is used to refer to people who undertake MHAOD research, who may or may not have a lived experience but are NOT in an identified Lived Experience or Peer research role or working actively and openly as a Lived Experience/Peer researcher, and who hold other positions within organisations including as clinicians, practitioners, academics, or professional researchers.

*For terminology used in the tool see *

PARTICIPATORY RESEARCH

Co-design research sits on a continuum of research participation. Participatory research describes ways of doing research that includes involvement of, or partnership with, people with lived/living experience, who are usually the subjects of research. Sherry Arnstein (1969) describes levels of 'citizen participation' in organisations and institutions, arguing that they range from 'non-participation' to 'tokenism' to genuine partnership and citizen leadership. Similarly, there are levels of lived experience participation in research ranging from:

- **high-level research participation** of genuine partnership and leadership, where research is 'done with' or 'done by' people with lived/living experience.

- **mid-level (tokenism) research participation** where people with lived/living experience are consulted but have little influence over the research, which is to say it is 'done for' people with lived/living experience.

- **low-level or research 'non-participation'** where people with lived/living experience are excluded, or research is 'done to' them as participants or subjects in a project.

(Bellingham et al., 2022)

This hierarchy does not seek to imply that mid- or low-level participation has no value. Indeed, early consultations (mid-level participation) can help to build dialogue and trust with communities, and non-participation (low-level) research may be used to determine community experiences, needs, priorities and/or capacities. Nonetheless, mid- and low-level approaches are less participatory and, therefore, may be less meaningful, resonant, or relevant to communities, and in many cases do not meet community expectations for co-designed research (Gardner & McKercher, 2021).

SIMILAR WORDS, DIFFERENT MEANINGS

Participatory research has many different names, which can be confusing. These include (but are not limited to) co-design, co-production, co-inquiry, co-construction, 'personal and public involvement' (PPI), and participatory action research. Many collaborative approaches share common elements, however they refer to approaches with different histories and influences. Confusingly, these terms are often used interchangeably, or used to refer to very different levels of participation. For example: the term 'co-design research' is sometimes used interchangeably with 'co-production research'; and the term 'co-design research' has also been used to refer to very different levels of participation, ranging from high-level partnership in all stages of the research process through to participation levels that would be described as consultation.

Even more confusing, conventional researchers may use terms such as co-design research, but in reality, there is little to no collaboration with people with lived/living experience evident in their work, or collaboration has been with other key stakeholders (e.g., clinicians) rather than people with lived/living experience who would be most impacted by an initiative or intervention. This incongruence can be misleading and potentially harmful to lived experience communities, who enter the research process with expectations of partnership, which can also be a hinderance to future substantive co-design research as it may create community mistrust, disempowerment, disengagement, and cynicism. Prior to labelling research 'co-design', it is vital to understand and reflect on the research team's processes and, what McKercher (2020) calls, "mindsets", to collaboratively determine whether the co-design research process and mindset meets (at least) lived experience community minimum expectations.

LEVELS OF RESEARCH PARTICIPATION

Doing BY

Led & owned by Lived Experience and/or Peer Researcher

- 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.
- Decision-making is shared and equitable, and all decisions related to the project are made together
- 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/living experience/peer perspectives are privileged in discussions.

Co-design

- Lived Experience and/or Peer researchers have experience relevant to the area of the research study, and work in partnership with conventional researchers in all stages (substantive) or key stages (bare-minimum) of the research process.
- Decision making is shared and equitable, and decisions related to, or that impact, co-designed elements of the project are made together
- Number 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/living experience/peer perspectives are privileged in discussions.

Doing FOR

Reference group or Advisory group

- A group of people with lived/living 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 the research project. The conventional researcher is the expert and owner of the project and research.

Consultation

- One or more person/s with lived/living 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/living experience have no power over the research design or process.
- Conventional researchers gather data on people with lived /living 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/living 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-DESIGN AND EPISTEMIC JUSTICE

A (VERY) BRIEF HISTORY OF CO-DESIGN

Co-design is a term that has multiple influences and has been used to mean different things in different contexts. As Szchzepanska (2020) notes, it arguably originates in 1970s Scandinavian 'co-operative design' (also known as 'participatory design'), which originally focused on collaborative design of products, services, and workplaces with end-users (Zander et al., 2011). Scandinavian co-design incorporated collaborative and design elements as the basis for innovation, including democratic dialogue and prototype 'mock-ups' (Zander et al., 2011). Today, co-design also draws on other participatory approaches and design lineages, including (but not limited to):

- **Participatory-action research (PAR)**, which emerged in the 1970s in Europe and the United States and emphasized citizen participation, critical inquiry, and equitable decision-making as the basis for creating socially just services, organisations and systems (Langley et al., 2018);

- **'Inclusive design', 'universal design' or 'design for all',** which emerged in the 1990s and emphasised dialogue and design to create accessible products, systems and environments for people of all abilities, ages, genders, cultures etc. (IHCD, n.d.; Szczepanska, 2020);

- **'Human-centred design'** from the 1990s, which focuses on empathic engagement with consumers to understand their needs in the design of products and services (Szczepanska, 2020).

- **'Design justice' ('disability justice', 'design activism')** which sees the democratisation of design as a political act, where community-led design is used to create social impact (Costanza-Chock, 2020).

Although participation, dialogue and design are often at the core of co-design, the **influence of multiple lineages** means that in practice 'co-design' can refer to a **continuum of participation** from: empathic orientation towards the needs and voices of citizens; to democratic dialogue with citizens; through to equitable partnership with, and privileging of citizen priorities and perspectives.

LIVED EXPERIENCE COMMUNITY: NOTHING ABOUT US, WITHOUT US

Despite long-held demands for **'nothing about us without us'** from Disability, Consumer/Survivor and Peer movements, people with lived/living experience still tend to be recruited as subjects rather than active agents in research, or are consulted in ad-hoc ways, and their expertise is often undervalued (Scholz et al., 2019). The wider research community can also disregard and devalue lived experience research via claims of bias (Beresford, 2020; Happell & Roper, 2007; Martineau et al., 2020), which ignores the proven efficacy of lived experience leadership and partnership and associated improvements in the relevance of research priorities and outcomes, and quality of research interpretation and knowledge translation (Brett et al., 2012).

Lived experience activists, researchers and advocates argue that continuing practices of exclusion in research are systemic and discriminatory. They represent an '**epistemic' or knowledge injustice** that maintains dominant ways of framing and responding to mental distress and substance use that are often misaligned with the knowledge, perspectives, and needs of people with lived/living experience (Banfield et al., 2018; LeBlanc & Kinsella, 2016). People with lived/living experience have demanded transformation of how knowledge about people with lived/living experience is produced (Voronka, 2016), including requests for equitable partnerships through all stages of research as a matter of epistemic justice doing (Beresford, 2020; Leblanc & Kinsella, 2016).

THE BAR FOR CO-DESIGN RESEARCH

The Co-design Kickstarter sets the bar for co-design research. Drawing on the multiple lineages of co-design and lineages of thought from lived experience communities, it outlines **Co-design Research Essentials** – the processes and mindsets (McKercher, 2020) that are essential to all co-design research activities. It also sets out a **'Substantive Co-design Research'** approach, which is considered the 'gold standard' as it aligns with expectations from Consumer/Survivor and Peer Movements for meaningful and continuous participation through all stages of the research cycle. The Co-design Kickstarter also proposes a **'Bare Minimum Co-design Research',** which meets minimum expectations of lived experience communities for co-design and involves collaboration in key stages of the research cycle. It also discusses **'Faux-Design' Research,** where research may be promoted as co-designed, but is in fact conducted without meaningful partnership or power sharing, or undertaken in ways inconsistent with the lived experience community's understanding of what co-design means. Finally, the Co-design Kickstarter distinguishes between co-design research activities and co-design activities more broadly, e.g., co-design of an intervention.

CO-DESIGN RESEARCH		
Substantive Co-design Research	People with lived/living experience work as Lived Experience/Peer researchers in partnership with conventional researchers in all stages of the research cycle including co-planning the research, co-defining the research design, co-conducting research, co-analysing/co-interpreting research data and co-disseminating research. Tasks may be delegated to co-leads, at least one of whom is a Lived Experience/Peer researcher.	**GOLD STANDARD**
Bare Minimum Co-design Research	At a bare minimum, people with lived/living experience work as Lived Experience/Peer researchers in partnership with conventional researchers in key stages of the research cycle including, co-defining the research design, co-deciding deviations in the research design, co-interpreting research data, and transparent reporting on limitations of the co-design research approach.	**BARE MINIMUM**
'Faux'-design Research	The research may be labelled as co-design but there is no evidence that people with lived/living experience were co-deciding in key stages of the research. It may or may not include collaborative or consultative elements e.g., co-collecting and/or co-interpreting data, and/or co-dissemination of research.	

Not Research		
NON Research-based Co-design	People with lived/living experience are involved in co-designing an intervention, service, or system that involves co-deciding. However, people with lived/living experience are not involved in any related research. In a publication, it may be reported as a co-designed intervention or service etc., but should not be confused with co-design research.	

KEY: CO-DESIGN RESEARCH ACTIVITIES

Co-planning the research	Co-planning, including building relationships, discussing aims and objectives, location and project team, governance, roles, responsibilities, resources, including budget and timeframes.
Co-defining the research design	Co-defining the research design and study protocol, including 'research problem', population, aims and objectives, questions and/or hypotheses, methodology, conceptual framework, ethical issues, sampling, recruitment, data collection and analysis, and dissemination strategies. Roles, responsibilities, budgets and timelines may be revisited.
Co-conducting the research	Co-researchers work in partnership to undertake the research in accordance with the study design and protocol. Work is undertaken by a whole team or delegated to team members, including co-conducting the research (e.g. ethics application, recruitment, data collection etc.), and co-analysis. Co-interpreting data may occur and involves presenting data in a 'digestible' format to the whole team, or to lived/living experience community members or community organisations to interpret and contextualise findings to determine the value and meaning.
Co-disseminating the research	Co-writing/co-creating/co-presenting research outputs, including traditional publications and presentations that are accessible and meaningful to affected communities, which might include non-traditional outputs e.g., infographics, zines, podcasts or film etc. (Horner, 2016; Greer et al., 2018). All team members are acknowledged as authors unless otherwise requested.

'SUBSTANTIVE' CO-DESIGN RESEARCH

SUBSTANTIVE CO-DESIGN RESEARCH	People with lived experience work as Lived Experience/Peer researchers in partnership with Conventional researchers in **all stages** of the research cycle	GOLD STANDARD

SUBSTANTIVE CO-DESIGN RESEARCH CYCLE

First and foremost, Co-design Kickstarter advocates for **Substantive Co-design Research** as the 'gold standard' as it is consistent with calls from Consumer/Survivor and Peer movements for partnership with people with lived/living experience in MHAOD research. It involves people with lived/living experience, employed as Lived Experience/Peer researchers, co-deciding with conventional researchers in *all stages* of the research cycle. The research team has a co-design mindset, and collaboratively co-plans and co-defines the research design, co-conducts and co-disseminates the research. Details for each stage are presented below:

Co-planning the research

Collaboration begins at the outset of a project. A team of Lived Experience/Peer and conventional reearchers is established, including at least half of whom are Lived Experience/Peer researchers. Research team members build relationships, discuss aims and objectives, meeting locations and communication, governance, roles, responsibilities, resources including budget, payment, timeframes.

Please note!

Researchers may find co-planning difficult to achieve in practice due to limited funds to pay people with lived/living experience. Teams can consider applying for 'seed' funding to support the planning stages of the research process. Organisations and funders need to consider ways of paying people with lived experience to support this stage.

Co-defining the research design

The established research team act as co-researchers, with equitable decision-making power and co-define the research design and study protocol including: research problem and population, aims and objectives, questions and/or hypotheses, methodology, conceptual framework, ethical issues, sampling, recruitment, data collection and analysis, and dissemination strategies. Governanance, roles, responsibilities, budget and timeframes may be revisited

Co-design research loops are embedded in all stages

CO-PLANNING

CO-DEFINING

CO-DISSEMINATING

CO-CONDUCTING

Co-disseminating the research

Co-researchers or delegated co-leads engage in a process of co-dissemination of data. Co-interpretation of data may occur with the whole team or lived/living experience community groups/organisations to interpret and contextualise findings to determine the value and meaning. Co-writing/co-creating research outputs may include traditional academic publications and presentations as well as non-traditional outputs. All team members should be acknowledged as authors unless otherwise requested.

Co-conducting the research

Co-researchers work in partnership to undertake the research in accordance with the study design and protocol. Research is undertaken as a whole team or tasks are delegated to co-leads, one of whom is a Lived Experience/Peer researcher. Co-researchers or co-leads co-conduct the research (e.g., ethics applications, recruitment, data collection etc.) and undertake co-analysis. The team meet regularly and review the study progress. Team roles, issues of power and inclusion may be discussed and re-negotiated.

CO-DESIGN RESEARCH ESSENTIALS

KEEPING THE 'CO' IN CO-DESIGN RESEARCH

Co-designing is co-deciding - Co-design research involves people with lived/living experience and conventional researchers co-deciding in the process of research. People with lived/living experience aren't simply consulted to 'voice' their perspectives on a research plan, design, conduct or interpretation. Instead, people with lived/living experience are employed as Lived Experience or Peer researchers and act as equal research partners in research decision-making processes. Working in partnership involves being intentionally democratic, sharing knowledge and power, and building each other's capacity to design new ways of understanding and responding to lived/living experiences of mental distress, trauma, and/or drug use.

Co-design research does not prescribe a particular research methodology or underlying (explicit or implicit) concepts of a research project. However, co-deciding with a mindset of sharing knowledge and power will influence the choice of methodology. Research methodologies that resonate with people with lived/living experience provide more understanding of lived experience perspectives or offer more opportunities for community participation (e.g., community participatory action research) may be favoured (Horner, 2016). Co-design research teams may also elect to conceptualise distress and substance use in ways that are non-medicalising or trauma-informed or focused around harm-reduction.

Co-design is a 'mindset' - Co-design isn't only a process of how research is done, it is a 'mindset' that aspires to being emancipatory (McKercher, 2020). The co-design research team shares an understanding that meeting the needs of affected communities requires listening, dialogue, building trusting working relationships, sharing knowledge, power and resources, and aiming for the highest level of participation possible (McKercher, 2020). This involves elevating or privileging the perspectives of people with lived/living experience. Positive discrimination in co-design research is necessarily disruptive and aims to promote new ways of thinking about a research problem, process, and interpretation. 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.

KEEPING THE 'DESIGN' IN CO-DESIGN

While co-design research is often bought undone by a lack of genuine co-deciding (power-sharing and collaborative decision-making), co-design research is also poorly served by a removal of 'design' elements. Done well, design can support democratisation of the research process as it can make visible decision points and decision-making to support the co-deciding process.

Incorporating design elements - Co-design research teams may use diverse design approaches to re-think a problem or solution, including, drawing/painting, prototypes, props, photos, meaningful objects, diagrams, digital media, mock-ups, maps, role-plays, theatre, movement etc. The 'best' design approaches for a particular project are created collaboratively by the co-design team through team discussion and exploration. This also allows space for culturally specific approaches to be explored and used. For example, First Nations people may wish to use creative ways of working that embed Aboriginal ways of knowing, being and doing such as Participatory Action Research-Dadirri-Ganma (Sharmil et al., 2021) or '8 Ways' (RAET team, n.d.), which embed practices such as yarning (respectful dialogue), Dadirri (deep-listening), Ganma (meeting of cultures and knowledge sharing), sharing stories, visualisation, symbols and metaphors, links to land and community. (Sharmil et al., 2021; Watson & Chambres, 2008; RAET team, n.d.).

Design is not a new form of expertise - Keeping the design in co-design is not about getting stuck on being 'designery', or about creative design becoming a new source of expertise for 'artsy' Lived Experience/Peer and conventional researchers. Rather, the mindset of co-design is about engaging in collective and creative approaches that move away from being reliant on text-based or academic ways of thinking and communicating and allow new knowledge to 'surface' (Langley et al., 2018). For people with lived/living experience, collective design can support communication and mobilisation of complex, experiential and embodied knowledge that may not be easily articulated (Langley et al., 2018), particularly given the historical exclusion of people with lived/living experience from research spaces and the corresponding lack of access to epistemic (knowledge) resources (LeBlanc & Kinsella, 2016). For conventional researchers, doing things differently by engaging with design elements can support them to challenge traditional notions of expertise and create space to see things differently (Roper et al., 2018). The aim is for the co-design research team to reflect upon what they might do to look at the problem from different perspectives and walk in each other's shoes.

CO-DESIGN RESEARCH LOOPS

Co-design research is not a one off, tick-box activity - Rather, drawing on influences from participatory action research (PAR), it involves cyclic and iterative processes of exploration, dialogue, action, and reflection (Lenette, 2022). In co-design research, these might be conceptualised as 'co-design research loops' across each research stage where team members (or delegated team members) engage in dialogue and design activities in non-linear cycles of: exploration and thinking together about the problem; synthesis and prioritisation of ideas; decision making and action; review of decisions and consideration of next steps.

DIALOGUE AND DESIGN ACTIVITIES

Exploration and thinking: Team members or delegated members share, discover, and explore diverse perspectives, experiences and knowledge through dialogue and design activities.

Synthesis and prioritisation: Ideas are examined and debated for their fit with community expectations, and evaluated, synthesised and prioritised by the team or delegated members. In this stage, dialogue and design may again be used to address gaps in thinking to ensure all perspectives have been considered.

Decisions and action: Decisions are explored, made, and actions are carried out by the team or delegated members.

Review and next steps: The team, or delegated members, reflect on decisions and determine the next steps required until the next stage of the research.

Exploration and Thinking

Synthesis and Prioritsation

Decisions and Action

Review and Next Steps
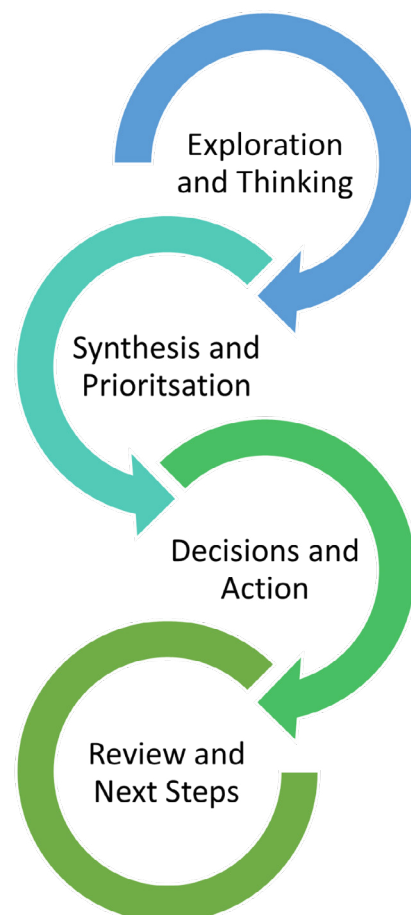
'BARE MINIMUM' CO-DESIGN RESEARCH
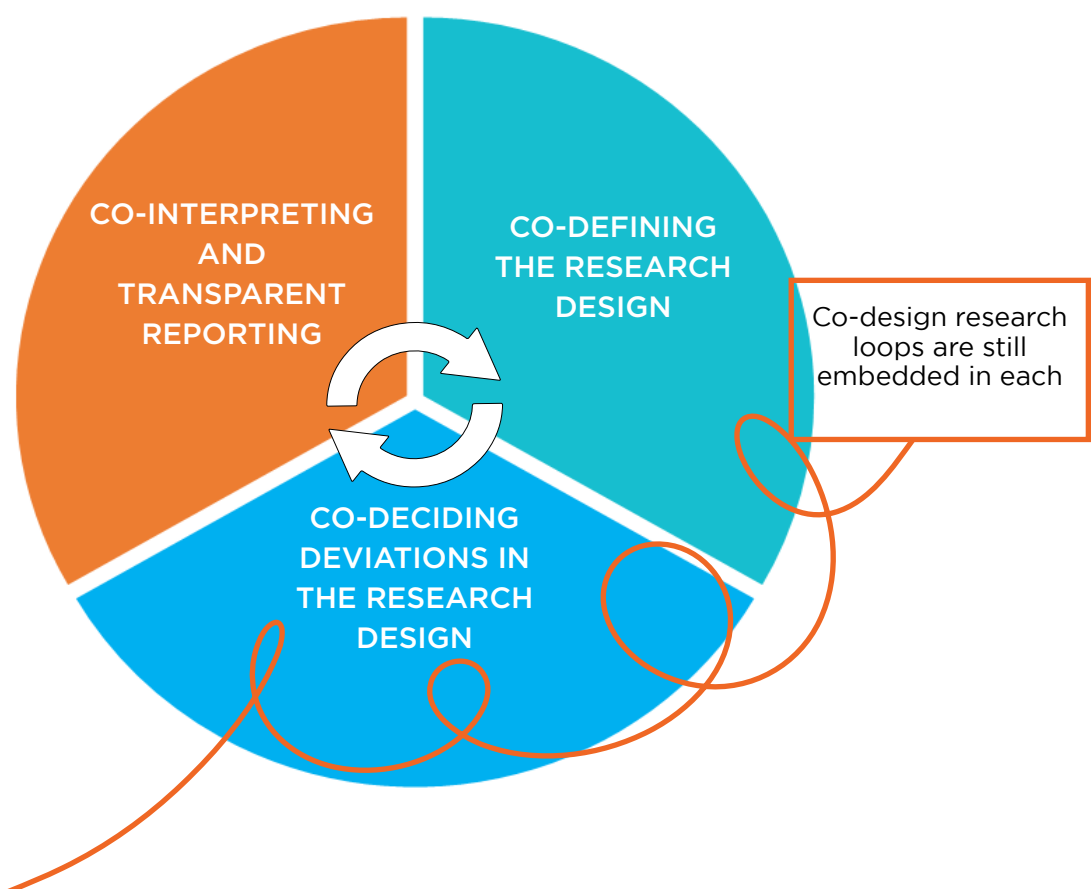
BARE MINIMUM CO-DESIGN RESEARCH	At a bare minimum, people with lived/living experience work as Lived Experience/Peer researchers in partnership with conventional researchers in **key stages** of the research cycle	BARE MINIMUM

This 'bare minimum' level includes researchers maintaining a co-design research mindset and viewing this level as a place to move from, rather than a place to settle.

Substantive co-design is the ideal. However, at times research teams may not be able to achieve partnership with people with lived/living experience through all stages of the research cycle due to fiscal or organisational issues. However, to meet minimum expectations of lived experience communities and to **'pass the pub-test',** co-design research would involve people with lived/living experience, employed as Lived Experience/Peer researchers, working in partnership with conventional researchers, co-deciding in *key stages* of the research cycle including: co-defining the research design; co-deciding deviations in the research design; and co-interpreting data and transparent reporting of the co-design research approach and limitations.

DOES IT 'PASS THE PUB TEST' FOR BARE MINIMUM CO-DESIGN RESEARCH?

CO-INTERPRETING AND TRANSPARENT REPORTING

CO-DEFINING THE RESEARCH DESIGN

Co-design research loops are still embedded in each

CO-DECIDING DEVIATIONS IN THE RESEARCH DESIGN

BARE MINIMUM: CO-DEFINING THE RESEARCH DESIGN

Even if Lived Experience/Peer researchers were not involved in co-planning the research (and determining researcher priorities) this stage still includes engaging in a meaningful process of reviewing initial plans, and potentially re-planning the project.

BARE MINIMUM: CO-DEFINING THE RESEARCH DESIGN

- **Co-defining the research problem and population -** Conventional researchers may have pre-determined a problem from the literature. This can be brought into discussions, but there remains a focus towards Lived Experience and Peer researchers considering this in relation to the needs of people with lived/living experience in relevant communities. It is important to remember that previous research may have minimal input from people with lived/living experience. This stage may also involve gathering further information on the problem (as new questions are asked), which may involve exploring a different body of literature as well as conducting community consultations.

- **Co-defining the study design -** This includes design of the study aims, questions, methodology, conceptual framework, ethical issues, sampling, recruitment, data collection, analysis and interpretation, and dissemination strategy.

- **Co-defining often leads to co-conducting and co-analysis -** In the design phase of a study, there are many decisions that are collaboratively made around who will collect and interpret data and how findings will be disseminated, including traditional and non-traditional research outputs to ensure findings are accessible to communities. If the co-design team (in an equitable decision-making process) determine that involvement of Lived Experience/Peer researchers in co-conducting, co-analysing and co-dissemination stages is required, then this becomes a necessary requirement of the study, and budgeted accordingly. If funds are limited, the co-design team may delegate this task.

BARE MINIMUM: CO-DECIDING DEVIATIONS IN THE RESEARCH DESIGN

Research design is rarely a one-off, linear decision-making process where a study design can be co-decided and then diligently (or not so diligently) carried out by conventional researchers. Rather, research is an iterative, reflexive, and sometimes messy process where elements may shift due to unforeseen contextual barriers and enablers e.g., due to requirements of ethics committees, challenges with recruitment, availability of study sites, unexpected or adverse events etc. (see 'Considering context').

Therefore, the design of a research study may need to be re-visited throughout the study duration. In other words, **co-design is not a permanent state of a project that can be ticked off**, it is an emergent property of the study that is maintained through an iterative, reflexive and relational process of collaborative and equitable decision-making.

Decisions about when and how Lived Experience/Peer researchers are contacted about any deviations in the study design are made in advance, and adequate time and funding is budgeted for this. This will involve creating a governance structure to determine how **macro and micro level decisions** are made.

- **Macro decisions -** If the study design is revised in any significant way a team meeting is called. During these meetings, co-design research loops are re-engaged: exploration, thinking about the problem; synthesis and prioritisation of ideas; decision making and action; review of decisions and next steps. In many ways, it may be likened to the parallel process of requiring amendments to ethics protocols when a research project changes. Indeed, if a change requires ethics amendments, then it is substantial enough to go back to the team involved in co-defining the research design.

- **Micro decisions -** For small, every-day decisions about the conduct of research, teams can consider ways to optimise collaboration. Group messages, online co-working sites, or other methods may be established for supporting decisions to be made collectively, or alternatively, a Lived Experience/Peer researcher with established connections may be designated to represent the interests of people with lived/living experience in the co-design team. They would be employed or consulted to make decisions or determine whether the co-design team need to re-convene. Employment is ideal given the speed and frequency of decisions during the conduct of research. However, if consultations are used, the Lived Experience/Peer researcher should be paid. Any micro changes to the research design would be transparently reported, including the rationale for the proposed change. This is a necessary lived experience community requirement for research to be called co-design to ensure accountability of conventional researchers to the co-design team.

BARE MINIMUM: CO-INTERPRETING FINDINGS AND TRANSPARENT REPORTING

Co-interpretation of research data is another minimum requirement for co-design. It involves Lived Experience/Peer researchers involved in co-defining the research design coming back together to interpret data, or interpretation of findings with communities of people with lived/living experience (as determined by the team involved in co-defining the research design). This includes discussion of the relevance, resonance and verisimilitude of the findings. Co-interpreting is required to contextualise and determine the meaning of research findings to affected communities. It is important for closing the loop (sharing research outcomes with research partners) and changing knowledge and it ensures those most impacted by research informed policy and services have equal power over any final presentation and interpretation of findings.

Transparent reporting Transparency about the co-design approach and processes undertaken is vital. This includes reporting where and how Lived Experience/Peer researchers were involved in co-deciding, and any factors that limited the team from engaging in substantive co-designed research. Transparency is vital since non-disclosure means that power and participation is hidden, creating a lack of clarity in the research literature. This leaves researchers, including Lived Experience and Peer researchers, unable to assess the level of decision-making power and participation of people effectively and fairly. Transparent reporting might include declaration of issues related to structural factors, logistics, time frames, budget etc., which can then support further advocacy efforts. Along with limitations, researchers should report recommendations to other research teams, who may wish to achieve a higher-level of participation in future studies.

'FAUX-DESIGN'

FAUX-DESIGN	The research may be labelled as co-design but there is no evidence that people with lived experience were co-deciding in key stages of the research. It may or may not include collaborative or consultative elements e.g., co-collecting and/or co-interpreting data, and/or co-dissemination of research

Co-design Kickstarter distinguishes **'faux-design' research** as 'nominal' approaches that do not meet the minimum expectations for co-design research as advocated for by Consumer/Survivor and Peer movements and lived experience communities. This is not to say that the research undertaken using these nominal approaches has no value. Studies might involve some consultative and collaborative elements e.g., community consultations, co-collecting, co-analysing, co-interpreting and/or co-disseminating data. **However,** there is *no evidence* that people with lived/living experience were involved as equal partners in co-deciding during key stages of the research cycle: co-defining the research design, co-deciding deviations in research design, and co-interpreting findings, and/or there is not transparent reporting. Without demonstrated power sharing, equitable co-deciding, or transparency, research is ultimately controlled by conventional researchers and the status quo of 'epistemic' injustice is maintained.

CO-DESIGN RESEARCH KNOW-HOW

Below are some important considerations for researchers wishing to engage in substantive co-design research or at least meet the minimum expectations for co-design research.

PREPARING THE GROUND

The key players - In co-design research, at least half of the co-design research team are Lived Experience/ Peer researchers (people with a lived experience of mental health challenges or substance use who use their experience and links to community in their research work). They are "the key players, the people who everyone else has a stake in" (Daya, 2020), and are working in designated lived experience research roles.

This work takes considerable skill, knowledge, and expertise; including understanding how to use lived experience in research, managing the affective and cognitive labour of being 'out' in a professional context, having less epistemic and structural resources to challenge dominant perspectives, and risk of exposure to stigma and discrimination in research teams (Bellingham et al., 2021; LeBlanc & Kinsella, 2016). If they are researching within a service or organisation, it is also expected that Lived Experience/ Peer researchers have academic freedom and can discuss critical perspectives on that service or

The key stakeholders - Other members of the co-design research team are key stakeholders e.g., conventional MHAOD researchers, clinicians, peer workers, family/carers, managers etc. Key stakeholders are not interchangeable with Lived Experience/Peer researchers. This includes peer support workers, who are employed to use their lived experience in health services or organisations. Peer support work is a distinct discipline and practice that requires a different set of skills, knowledge and expertise, and has a different orientation and relationship with a service or an organisation, and different expectations and constraints in their role, compared to that of a Lived Experience/Peer researcher.

Clinicians or conventional researchers may also have a lived experience. However, they do not have the same expertise, or manage the same affective and cognitive labour, as a Lived Experience/Peer researcher. Wearing two hats (e.g., as a clinician or peer worker and a Lived Experience/Peer researcher in the same co-design research team) can also undermine the value of Lived Experience/Peer research, particularly when the co-design research team might struggle to determine what perspective the clinician or peer worker is seeking to advance.

Family and carers also have a lived experience but cannot be substituted for a person with lived experience of mental health challenges or substance use. This is because family and carers concerns, needs, and perspectives differ to those of people with lived/living experience. However, family and carers may be key stakeholders in a co-design research team if the research problem needs to be understood from a family/carer perspective.

Partners not participants - Lived Experience/Peer researchers are colleagues and co-researchers NOT participants (Roper et al., 2018). Teams do not need ethics approval for the involvement of any research partners, including Lived Experience, Peer, or conventional researchers. However, co-design research teams of Lived Experience/Peer and conventional researchers may recruit people, including people with lived experience, as participants or subjects for a study that would require ethics approval.

PREPARING THE GROUND

Payment matters - Lived Experience/Peer researchers in co-design research teams need to be paid fairly and formally for their work (Papoulias et al., 2022). Due to the historical disempowerment and underpayment of people with lived/living experience, it is important that the research team engage in transparent discussions about power and pay, and acknowledge Lived Experience/Peer researcher skills, knowledge, and expertise (See Papoulias et al., 2020). 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 (Greer et al., 2018).

Teams may also need to challenge organisational and institutional demands for traditional credentials. Lived Experience/Peer researchers are paid as employees or contractors, with employment being prioritised if preferred by the Lived Experience/Peer researcher. Some people with lived/living experience may prefer other payment methods such as vouchers or honorarium. However, this should only be used if this is preferred or requested by the Lived Experience/Peer researcher, as opposed to being the preferred method of the service or organisation.

Some Lived Experience/Peer researchers may wish to work as volunteers in service to an affected community. If volunteering, we would suggest that at a minimum a donation is made on the behalf of the person to their chosen charity. However, this should only be considered if it is the preferred option of the Lived Experience/Peer researcher rather than of the organisation.

Organisations and institutions should consider strategies and opportunities for supporting the co-planning stages of co-design research, as well as opportunities for ongoing and secure employment for Lived Experience/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/Peer researcher skills, knowledge, and expertise, including experience in Lived Experience/Peer led, co-production and co-design research.

Considering context - In co-design research, the impacts of broader social structures on the research process are carefully considered. For example, the impacts of policy and contemporary social values on Lived Experience/Peer researchers, including issues of stigma and discrimination, as well as criminalisation, that might come with self-disclosure (LeBlanc & Kinsella, 2016). The team should respect the preferences of Lived Experience/Peer researchers for confidentiality (if desired) and take into account the impact of visibility in the research (Bell & Pahl, 2018). Supportive organisations can also develop language and conduct guides with people with lived/living experience and make these available to researchers. See for example the guides developed by NADA (2019) and MHCC (2022).

PREPARING THE GROUND

Seeking diversity and disruption - In co-design research, teams are composed of Lived Experience/ Peer researchers and conventional researchers with a diversity of relevant experience, knowledge, expertise, 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 (LeBlanc & Kinsella, 2016; Brett et al., 2012).

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 be invited to a 'first meeting' or informal chat. Lived Experience/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 (Daya, Hamilton & Roper, 2020).

Lived Experience/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, knowledge, and experience in working collaboratively with people with lived/living experience. The process of ensuring diversity within the team may be ongoing as the project planning and design of the project emerges.

DOING THE WORK

Addressing power and attending to relationships - In co-design research, conversations about power are explicit. Teams practice deliberate egalitarianism by considering how power might silence people with lived/living experience and by working to elevate lived experience perspectives. Also, the voices of Lived Experience/Peer researchers are amplified by ensuring that people with lived/living experience make up (at least) half of the research team (Daya, 2020; Roper et al., 2018). 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 (Lignou et al., 2019). For a guide on how to navigate discussions about power, see [Roper et al. (2018) power exercises.](#)

Time, place, and communication - Co-design research 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 often exclude people with disabilities and fluctuating capacity (Berg & Seeber, 2013). Co-design research teams may need to challenge organisations and funding agencies that state a commitment to co-design research but are focused on speedy deliverables.

DOING THE WORK

Time, place, and communication - Organisations and funding agencies can support co-design by providing the time and resources and remaining in dialogue with the co-design research team about the project timeline and deliverables. Place is also an important consideration. People with lived/living experience may have had traumatising interactions within healthcare services in some locations, and meeting in these locations may be a barrier to participation (Greer et al., 2018; Horner, 2016).

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/Peer researchers may require reasonable adjustments to the co-design research 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-design research work, which is often transgressive to current ways of knowing and doing. Finally, communication needs to be adapted for the needs of all researchers (Daya et al., 2020).

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/living experience in research, but "it's even more important to be honest about where you are". Daya provides a checklist to assess the participation possibilities for a project if the team is unsure.

Aspire don't settle. Even if you can't do substantive co-design research right now, the 'bare minimum' level is a good place to start and will build the skills and knowledge you need to do substantive co-design research. Also seeking external training and support in co-design research 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-DESIGN KNOW HOW?

A BOOK ON CO-DESIGN

Kelly Ann McKercher (2020). Beyond sticky notes.

Sydney, Australia:

www. beyondstickynotes.com

This book is not specifically about research, but provides an excellent overview and details about methods and processes of co-design.

CO-DESIGN CHECKLIST

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-design.

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, which shares many aspects of substantive co-design, and how to have conversations about power. It includes some case study examples.

## HOW TO CREATE DIVERSITY IN PARTICIPATORY RESEARCH TEAMS

Indigo Daya, Bridget Hamilton and Cath Roper (2020). Authentic engagement: A conceptual model for 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. This resource outlines the multiple experiences and perspectives of people with lived/living 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 precarieties of pay for Lived Experience and Peer researchers. British Journal of Social Work, 51. doi: 10.1093/bjsw/bcaa241 This paper looks at issues of working conditions and pay for Lived/Living Experience and Peer researchers.

CONSIDERATIONS IN CO-DESIGN
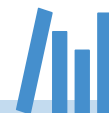
Yasmine Beebeejaun and colleagues (2015). Public harm or public value? Towards co-production in research with communities. Environment and Planning C: Government and Policy, 33. doi:10.1068/c12116 This paper considers key ethical issues in participatory research and how we might re-think the relationship between the researcher and the 'researched'.

INSTITUTIONAL BARRIERS AND ENABLERS TO CO-

Stan Papoulias and Felicity Callard (2022) Material and epistemic precarity: It's time to talk about labour exploitation in mental health research. Social Science & Medicine, 306, doi 10.1016/j.socscimed.2022.115102. This paper examines the conditions under which people with lived/living experience labour in mental health research, pointing to the material and epistemic precarity of this work.

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.

TAKE THE QUIZ - ARE YOU CO-DESIGNING?

McKercher, K.A. (n.d.)

But is it co-design?

This quiz provides a quick overview of key requirements for co-design.

TERMINOLOGY USED IN THIS TOOL

LIVED/LIVING 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-DESIGN RESEARCH TEAM	A research team comprised of people with lived/living 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/living 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/living 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/living 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/living experience.

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