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Sydney Policy
Lab

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Illuminating Lived Experience *Exploring Researcher Perspectives on Co-design Through Participatory Methods*

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Acknowledgment of Country

The Sydney Policy Lab acknowledges the generations upon generations of Traditional Custodians that have held responsibilities for Country, “custodian-ing” it from one generation to the next. We acknowledge the cultural protocols of protecting and holding knowledges that have sustained culture and Country for over 60,000 years.

Based in Sydney, we acknowledge the Gadigal Elders, past and present, and the beautiful Gadi Country where we work. We extend this acknowledgement to the Country, Elders and Ancient Ones of many other First Nations communities across Australia. We honour and respect the sovereignty of the many Nations where we live and work.

We are committed to working respectfully with First Nations communities across these beautiful lands, seas and skies.

Sydney Policy Lab

The Sydney Policy Lab was created by the University of Sydney to be a multidisciplinary, non-partisan space where the academy and community can come together to investigate and solve complex policy issues that face our world, build community and make progress. It represents a powerful contribution by the University to the common good.

It was created by people searching for practical answers to the question of how we can best arrange our life together. Its work reflects this, building relationships with and between people from diverse backgrounds to encourage greater empathy and understanding, and supporting them to create community-led policies. In particular, we want to work with those who have been excluded from power.

Lab Notes are the Sydney Policy Lab’s papers on methodology. They focus on how community-centred policy is made, sharing the thinking and techniques that shape how our collaborators work. This is the first publication in the series.

Australia Cares

The Sydney Policy Lab initiated this methodological research to inform the design of the Australia Cares project’s first phase (2022–2023).

Australia Cares aims to radically transform Australia’s systems, practices and cultures of care by elevating the significance and importance of care in society. This initiative has emerged from a diverse coalition of people across care communities, researchers and policymakers. This is not another welfare reform project, but something that aims to challenge the way we live and the way we organise our communities. Building on the momentum for change generated by the COVID-19 pandemic, the goal of this initiative is to help Australia become a more caring nation. A priority for this transformation of care is listening to and sharing power with people who give and receive care.

illuminating Lived Experience

Exploring Researcher Perspectives on Co-design Through Participatory Methods

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60 second summary

While there is a growing scholarly interest in lived experience research and different kinds of participatory methodologies in research and policymaking, there is a lack of clarity about core underpinning concepts and reasons for engaging in co-design work. Our team of co-authors are researchers, many of whom have lived experience relevant to their areas of research. Many of us undertake research with relevant lived experience and have been research participants as well as researchers. We have come together to offer cross-disciplinary insights on key elements and practices of participatory approaches and strategies for powerfully engaging lived experience in research processes.

This report considers how people with lived experience, including those from diverse backgrounds and communities, who have often been excluded from power, can be co-collaborators in research, holding equal share of power. In particular, we have explored how researchers can establish genuine partnerships and have articulated a set of core principles. We also draw insights from communities and people with lived experience about how they can be valued and listened to in research intended to improve policy and practice.

In doing so, this report problematises and nuances concepts like co-design that we believe have become oversimplified and reified. We explore a wellspring of research methods and tools that others might like to draw from and add to, identifying key elements and practices consistent with a participatory approach. The report explores the critical role of sharing power across the research lifecycle. Finally, we address pitfalls, such as avoiding tokenism, and explore practical considerations to support the participation of people with lived experience, including reciprocity and appropriate timelines for genuine involvement.

We make the case that lived experience research and co-design methods are distinct concepts. Lived experience research can take many different forms, including methods that are not co-design. On the other hand, genuine co-design methods necessitate the involvement of people with relevant lived experience and other affected communities as deeply as possible throughout the research process.

We pose three questions that can guide research design and elicit reflection and action from researchers and research teams, including ourselves:

1. How are we ensuring our relationship practices with persons and communities are reciprocal and not extractive?
2. How are we including people from diverse communities, at their discretion, as active and equal members of the research teams, in ways that they can exercise agency and autonomy?
3. How are we collaboratively evaluating and identifying tangible evidence that our collaborators benefit from the processes of their involvement, and from the outcomes of the research?

We hope that this report sparks debate and discussion about different participatory approaches in and beyond the methods discussed here. Our aim is to encourage researchers to be creative in the ways co-design and lived experience are approached, while being true to the critical roots of participatory methodologies.

Introduction

Everyone gains when researchers partner with the public and policymakers. The knowledge generated is more likely to be useful to society and should be encouraged.¹

Increasingly, academia, government, business and communities are involving people with lived experience in research, design and policymaking. This report is written from the perspective of researchers with experience in conducting lived experience research, many of whom have lived experience relevant to their research.² Our aim is to illuminate perspectives on lived experience methodologies and considerations for authentic engagement of lived experience collaborators in co-design.

This report seeks to make four initial contributions to understanding the potential and challenges of lived experience research within academia by:

1. clarifying terminology of lived experience and co-design in different contexts
2. sharing a wellspring of methods and tools from examples based on our experiences
3. identifying practical considerations when it comes to the inclusion of people with lived experience, such as financial compensation, in-kind support and avoiding tokenism
4. exploring strategies for overcoming barriers to co-design in research and policymaking.

We emphasise that lived experience research and co-design methods are distinct approaches. Lived experience research can take many different forms, including methods that are not co-design. Lived experience research can be led and conducted by people with lived experience or involve them as co-researchers or advisors. In contrast, co-design methods necessitate the involvement of people and communities with lived experience as deeply as possible throughout the full lifecycle of the research process. Our aim is to encourage researchers to be creative and playful in the ways they approach co-design and lived experience research, while being true to their foundational principles.

The Sydney Policy Lab initiated this research as part of its Australia Cares initiative. The Lab brings together academics, policymakers and communities, supporting people from diverse backgrounds to create community-led research and policy solutions. To do this, the Lab draws on different participatory approaches such as participatory action research, community organising, the relational

method, deliberative democracy, co-design and community-led research methodologies, including Indigenous research methodologies, to inform policymaking. Each of these methods shares a deep respect for different forms of knowledge and knowledge-creation, including knowledge that comes from diverse lived experiences.

Australia Cares aims to radically transform Australia's systems, practices and cultures of care. This project has emerged from a diverse coalition of people across care communities, researchers and policymakers. It is not another welfare reform project, but rather an endeavour that aims to challenge the way we live and the way we organise our communities. Building on the momentum for change, kindness and inclusion generated by the COVID-19 pandemic, the goal of this initiative is to help Australia become a more caring nation. A priority for this transformation of care is listening to and sharing power with people who give and receive care.

Background

Lived experience means different things in different contexts. When it comes to social movements, the development and use of the phrase 'lived experience' has been inspired by the call of disability rights activists: Nothing about us without us. This phrase is also taken up by many other marginalised communities, including Aboriginal and Torres Strait Islander Peoples. Disability-led organisations and disability studies continue to be leaders in 'lived experience-led' methodologies. In medical research, engaging people with lived experience is fast becoming a norm. Research has been conducted with people with lived experience of dementia, cancer, obesity, long COVID-19 and chronic pain. In mental health, there is an emerging "lived experience movement," that builds on a much older mental health consumer movement.³

The lived experience movement is also seen in approaches to citizen participation and the "deliberative wave" of democracy.⁴ It has also become prevalent in responses to violence against women and family violence more generally, with governments investing in Family Violence Lived Experience strategies.⁵ Additionally, there is an expectation that the conduct of research that affects Aboriginal people and communities involves the people it affects, and where possible includes researchers with lived experience as prescribed in the AH&MRC of NSW Ethical Guidelines.⁶ These movements have foundations in critical theory, an

approach that aims to surface, critique and challenge the nature of power in society and its impact on persons, people and populations. Critical theorists contend that societal problems and challenges arise from dominant – and often assumed – social structures and embedded cultures, and that through the emancipation of communities, these power structures and cultures can be demolished and rebuilt.

Politically, a commitment to lived experience has become increasingly central to calls for human rights and self-determination. The “PANEL” principles of participation, accountability, non-discrimination, empowerment and legality are at the core of a human rights-based approach to policymaking.⁷ The United Nations Convention on the Rights of Persons with Disabilities,⁸ the United Nations Declaration on the Rights of Indigenous Peoples,⁹ Uluru Statement from the Heart and the 2023 Voice to Parliament constitutional amendment proposal are groundbreaking examples of increasing accountability of governments to maintain the rights of people with lived experience and cultural identities to full participation in decisions that affect them. Indigenous Data Sovereignty, Community Control, net benefits to community, costs reimbursement, cultural sensitivities,¹⁰ rights and embedded participation and governance are further prominent examples of structures intended to enable Aboriginal and Torres Strait Islander Peoples’ voice in decisions that affect their lives.

Much like lived experience research, co-design also has different applications in different contexts. As a collaborative method to designing products, systems, processes or policies, co-design is applied in situations where collaborators from across disciplines work together from the outset to achieve a common goal. It is a commonly used approach in settings ranging from service design in the public sector to software design, tech industries and commercial product design, to name a few examples.

This report is primarily about lived experience co-design and related methods as applied in academic research. Any approach that includes people with lived experience benefits from clarity around core principles, noting that those of co-design typically include being inclusive, strengths-focused, outcome-orientated, iterative, participatory and creative.¹¹ There are nuances and specificities when applying lived experience and co-design methods in academic research contexts that warrant further discussion.

The increasing recognition of lived experience voices and the rise of co-design research methods has had some overlap. Indeed, the concepts are often confused or used

interchangeably. As such, it is worth explicitly setting out what makes them different:

- Co-design, and other methods like co-production, seek to co-create. Co-design is a type of research method that seeks to privilege or centre the voice of community participants with lived experience by ensuring they are equal collaborators and full partners throughout the full research process, from identifying research priorities, designing methods and data collection, interpretation and analysis, all the way to shared authorship and implementing impact strategies.
- Lived experience research is a broader category, which seeks to privilege the voices of people with lived experience but may not necessarily seek to co-create. For example, people with lived experience may only be involved at specific stages of a research process, say, on an advisory group, as participants in workshops or subjects for data collection. Different levels of participation in research exist, and depending on how people with lived experience are involved in the research, they may have limited power to exercise influence over the project and its outcomes. (See the summary in table 1.) For example, in this type of work, researcher-led approaches that engage community, such as ethnography, are common. While they can entail the researcher embedding themselves in participating communities and can even involve the researcher being from the participating community, the research questions and data collection are the domain and decisions of the researcher.

Doing by	Research led and owned by lived experience and/or peer researcher	High-level participation: genuine partnership and leadership
Doing with	Co-production	
	Co-design	
Doing for	Reference group or advisory group	Mid-level participation/tokenism: consulted but little influence
	Consultation	
Doing to	Subject/participant	Low-level/'non-participation': excluded research is 'done to' them as participants or subjects in a project
Exclude	Coercion/ Manipulation/ Exclusion	

Table 1. Levels of research participation¹²

As Bellingham et al. explain in their *Co-Design Kickstarter*, the hierarchy of these levels of participation does not necessarily imply mid- or low-level participatory approaches should always be avoided or are of no value. It is, however, crucial that researchers ensure they don't equate these methods to co-design, are careful not to raise community expectations regarding their role and influence, and are mindful about the limitations of the approaches. Alternatively, these approaches may serve as early research phases or building blocks of more participatory research design. For example, "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" that inform further research design and partnership.¹³

Importantly, researchers who fail to include and genuinely involve the communities that they are researching risk producing questionable results at best. They are also placing their reputations and as well as their studies in jeopardy. As illustration, a large-scale autism study, Spectrum 10k, was paused following ethical concerns raised by autistic advocates around topics of representations, and fears of findings being applied towards the advancement of eugenics.¹⁴

Beyond the question of involving people with lived experience in research is the value of lived experience researchers. For example, a pressing policy issue is an ongoing scarcity of people with lived experience of disability who are employed as researchers.¹⁵ Representations of scholars with disability can be especially modest on occasions where accommodations are required.¹⁶ There is also a scarcity of Aboriginal and Torres Strait Islander academics across a multitude of disciplines and increasing reports of racism in academic settings. In this report, we therefore aim to investigate and advise about evidence-based ways in which research and policy activities can become more inclusive of the communities that are studied and impacted upon.

Method

This research has been a collaboration between researchers drawing on lived experience methodologies across disciplines. Co-authors of this report have been drawn to lived experience research in different fields and disciplines at The University of Sydney, with a view to having a positive impact in the world. The fields in which we work include:

- community organising and mental health (Amanda Tattersall)
- nursing and person-centred care (Brendan McCormack)
- law, family violence and multiculturalism (Ghena Krayem)
- business and education (Elaine Huber)
- pharmacy with a focus on medication management in people with dementia (Mouna Sawan)
- people, place and the systems within with a focus on business, governance and Indigenous Peoples (Katie Moore)
- disability studies and in particular research that informs about redressing ableism and advancing the economic and social inclusion of people with disability (Damian Mellifont)
- collaborative policymaking (Lisa Fennis)
- the union movement (Marj O'Callaghan)
- children and family social work (Amy Conley Wright)
- peace studies and process philosophy (Juliet Bennett).

Many of us undertake research with relevant lived experience and have been research participants as well as 'researchers'. This includes Katie who is Wiradyuri and has worked across many areas of Indigenous rights development; Amanda who has bipolar and researches mental illness; Elaine who has been a student at many levels and now leads educational co-design practices with students; Mouna who is a carer and pharmacist and is leading research programs to co-design interventions to

optimise medication use in people with dementia; Ghena who is a Muslim woman who has led several projects that have involved understanding the lived experience of Muslim women in Australia, often dealing with the challenges of being part of that community; Amy who is a parent of a child with disabilities and has conducted research on advocacy by parents of children with disabilities; and Damian who has led and co-produced many studies supporting the social and economic inclusion of people with disability.

The collaborative research process was organic and respectful at every stage. Sydney Policy Lab initiated the research through Juliet. Juliet connected with Amanda and Ghena, who had been planning a similar research project and drafted the initial interview questions. Juliet shared the invitation for involvement at a co-design community of practice workshop at The University of Sydney. This first stage of the research then involved Juliet undertaking one-to-one conversations with each co-author, complemented by a review of key grey and academic literature recommended by co-authors. She transcribed the interviews and led the analysis, adding to this from scholarly literature and drafting the initial manuscript. This was followed by an iterative process with co-authors: meeting for group discussions and an asynchronous discussion via comments within the shared document, adding examples, writing, shaping and editing the report together. Amanda and Brendan had prominent roles in the interpretation and iterative manuscript revision. Amy copyedited the report. All of the authors contributed to the revising the report critically for important intellectual content and approved the final manuscript.

The report is itself a dialogue that honours the tradition of critical theory and participatory research. The authors of this report do not agree on everything. Together we recognise that no one idea is 'right,' and that, just like in participatory research processes, the best ideas are forged in relationships. Different perspectives are highlighted by quotes attached to a co-author's initials. This gives a more conversational tone to the piece and acknowledges our dual role in this report as researchers and participants of the research.

We are each embedded in a variety of participatory methodologies, which inform our practices and research in our respective fields (see Appendix 1). The methods we use are underpinned by a philosophical commitment to participation and inclusion, and the principles articulated in this paper. Still, the methodologies are very different in how we go about them, and the choices they involve. Like any inquiry, our findings are partial and will continue to develop over time. Our intention is not to be exhaustive nor

prescriptive, but to instead offer up a conversation in public, coloured with examples and oriented to a variety of participatory methods.

We sought to apply Max Liboiron's equitable and participatory approach to selecting the order of authors.¹⁷ This involves getting all contributors together, discussing what makes the report unique and important and what labour was done and by whom, ranking first in terms of labour contributions, and then reordering with consideration to social location and social justice. As we started this process a consensus emerged around the lead author drafting the author order, in conversation with authors, based on the above principles to make sure everyone felt it was fair to all involved.

1. Critical roots of lived experience

We began our conversation in an exploration of terminology and methodologies. What is 'lived experience' research? How does lived experience relate to 'co-design', 'community-led' and other 'participatory' research methodologies? Each of these methodologies are distinct, while also sharing a set of core principles that we explore in this section. We argue that lived experience research methods are not always co-design, yet co-design should always include lived experience people and communities, deeply and creatively, throughout the research process.

What is lived experience research?

Lived experience research recognizes the inherent expertise of communities, and challenges existing power imbalances in policy processes.¹⁸

It is important to recognise that disagreements exist around the language attempting to describe research that is conducted by researchers with lived experience. It has been suggested there is no set definition of lived experience.¹⁹ However, in general the term 'lived experience' and associated terms such as 'lived expertise,' 'lived experience expert,' 'lived-experience-led' and 'people with lived experience,' are used to refer to people with direct or first-hand experience of a topic or issue of concern to research or policy. For example, lived experience of disability, illness, pain, domestic violence or homelessness.

While each person in our research team wishes to value lived experience knowledge equally with other forms of knowledge, disagreement among our team reflects the different perspectives that exist in the wider research community.

In our conversations about lived experience in research, three key themes or tensions emerged which are further discussed below:

1. Person-centredness and difference: Distinguishing lived experience as coming from first-hand experience. How can the uniqueness of one person's experience illuminate broader issues?
2. Identity and sameness: Reconciling the distinctness of each person's unique lived experience, and including lived experience people and communities in research

that affects them. What matters – the label or the consequence of the labelling?

3. Expertise and power: coupling lived experience with terms like experts and expertise – should we reinforce or disrupt hierarchical language?

Person-centredness and difference

Sometimes the term 'lived experience' is used in contrast to 'researcher' or 'professional'.²⁰ Some of us see this contrast or "identification with roles" as problematic:

We are *all* people of lived experience – what other kind of experience is there? Labelling some as those with lived experience allows the rest of us to hide behind our mask (usually a professional one) and not be our authentic selves. So, I like to think of us all as 'people of diverse experience' which forces us to be real persons in a collaborative space and as a result actively manage our power, privilege and influence (over). (BM)²¹

We all have lived experience, there is nothing in our life that is not lived experience. We have lived experience as members of different communities, friendships, families, workplaces, cultural backgrounds, illnesses we live with or have survived, as a user of services, as a customer of businesses.

The inclusion of lived experience as subject and method of research has clear ties to phenomenology, which reflects on mental, bodily and relational experiences of being in the world.²² When we speak to our lived experiences, we can only speak to one person's perspectives of their experiences of that thing, and even then, our words will fail to capture the experience as it was felt. Creative methods, such as art and poetry may get closer than anything else, but the experience, the Truth with a capital T, will never be captured.

This speaks to the uniqueness of every person's experience, which connects to 'person-centredness' and 'respecting the personhood of all persons':

There is no such thing as two people who are the same, ever. This comes up against the idea that I need to have a lived experience person in the room with me so that I can understand how to empathize with them appropriately. Because then I can see how

you live, and the rest of it. My argument is that even if I have 1000 people with the same “lived experience” in a room with me, I can still never understand them. I can never empathize with you. I am not you. I am not that person. So why do we create these false constructions? All I can ever do is *be alongside*, which is why I use the language of being *sympathetically present*. All I can do is work at understanding the perspective that you bring into a space, alongside the perspective that I bring into a space. Through this we develop a way of connecting that is respectful of both sets of lived experiences. It also links to the value of presencing, on being present, and also just respecting the fact we’re all completely different people. (BM)

We’re all different. And also, some of us are more different than others, and actually how we connect with each other on this is crucial. There is no reified researcher who objectively stands aside and just observes the world. And there is no reified co-design model everyone should follow. No one is the same. I’m not the same as you. So, then I need to listen to you. Therefore, I have to have research techniques that mean I acknowledge your dignity in the relationship - from the premise of difference the method flows. (AT)

An important point in lived experience research is to distinguish knowledge that is generated through direct, first-hand experience of a topic, from knowledge that comes from more distant or secondary experiences such as through books, media, or from another person audibly sharing their experiences.

In different lived experience research domains, there are critical types of lived experience being referenced. Within some contexts, such as disability, a critical distinction is between people with first-hand, secondary or tertiary lived experiences. For example:

For me as a neurodivergent researcher, I would argue that it’s critical not to confuse the first-hand experiences of having a disability and other experiences such as assisting people with disability, e.g. the experiences of carers. If a job advertises for someone with lived experience of disability, and a carer says, “Well, I have lived experience through somebody else,” that’s where I take issue. I completely recognise the roles that carers have in helping people, but when they begin to speak on behalf of, and claim to have that person’s lived experience - that’s where we’re saying nobody can have the lived experience of another person. (DM)

Lived experience can be classified under different categories, as an Aboriginal person, as a woman, as a person from Western Sydney. The individual experience is the same but is often categorised as a representation of a particular subset of the wider community. It can be quite different (or similar) to lived experiences of a person with disability or lived experience across a diversity sort of contexts. I think your credibility comes from how you identify a person with a said lived experience. And I think that tension between claiming lived experience and how you identify as someone representative of a broader community is critical. (KM)

There was a recurring theme that lived experience can shatter stereotypes and makes you question “the kind of issues different people are interested in and what kind of contribution they can make.” (MOC) Similarly, insights from lived experience can be surprising and powerful:

I was repeatedly struck by how much more visionary and progressive members were than union officials, and how much more they were willing to engage in those issues and take progressive positions. And then to be able to talk about housing or climate, with the first words in this sentence being, “I’m a cleaner at a shopping centre in Adelaide ...” to be grounded in a very ordinary experience made it so powerful. (MOC)

There is an ambiguity over what it takes to have lived experience or engagement with traditional or cultural knowledges systems that may sit outside the mainstream western knowledge structures. This opens a space for exploration of how identity intersects with lived experience.

Identity and sameness

What is ‘identity’ and what is ‘lived experience’? What’s a ‘form of knowledge’? There is a risk of conflating lived experience with identity and ideology. I think there’s a real relationship between the two that isn’t written up. It is important to clarify how people conceive of lived experience - as individualised or part of a community? (AT)

What are the parameters for lived experience? Depending on the context, does lived experience requires a diagnosis or is identifying with an experience or cultural heritage enough? There is also a need to distinguish individual lived experience - “my life” - and a collective sense of lived experience - “people who live like me.” The point is “not pretending that a single person can represent an identity as a philosophy is really important. So as lived experience you

represent your lived experience full stop.” (AT) This sentiment is reflected in the mantra that is associated with the autistic community, ‘You’ve met one of us, you’ve met one of us.’ There is an interesting tension between this and the mantra ‘nothing about us without us.’

It raises the question: How are researchers to reconcile the uniqueness of each person’s lived experience, and the value of including lived experience people and communities in research that affects them? As a group, this key tension was a sticking point for different perspectives, from which emerged a view that it is not the shared experiences sought to be captured by a label – ‘lived experience of [fill in the blank]’ – but the shared experiences that are a consequence of that labelling:

One person with dementia is one person with dementia. And that’s fundamentally it. And you can pack as many people with dementia into a room as you like, but you still have just a collection of individuals with dementia. But what binds them together will be some of their experiences in society. So, it will be more of the social kind of impacts that binds them together rather than the actual dementia itself. The dementia is almost irrelevant to the experience – it’s what they experience because they have that label or because they display particular behaviours associated with it, that society then puts all kinds of challenges in their way. (BM)

This structural dimension – a shift from focus on the person’s experience, to focusing on the societal experience – resonated across the group:

I can’t say, you know, “I’m neuro divergent, I speak on behalf of all neurodivergent people based on my own personal experiences.” But what I can say is that if it’s a study about neurodivergence, then there should be some representation within the team. This is coming back to the Nothing About Us Without Us. And again, coming back to the commonalities that you do have within those communities: the shared values and the shared experiences. You won’t have identical experiences. But anyone who’s disclosed neuro divergence, I can pretty safely say they’ve experienced ableism at some point. The risk is that you’re not going to have someone from the community because they’re one person. It’s sort of just cutting that off there and saying, well hang on a second, they’re one person but they’ve got many experiences that are shared within that community, and chances are they are connected with that community. (DM)

The point is that it is not the lived experience category but the common societal experiences as consequence of that label. Who is defining the identity of particular communities and particular experiences is really important:

When people in power or decision makers are talking about Aboriginal and Torres Strait Islander Peoples for so long it has been focused on a negative stereotype or a deficit model. We are really trying to reframe it: that there’s a significant strength in those cultures, and there’s a strength in that identity. To question who gets to define that personal identity and how we define that through lived experience, to ensure that we are really bringing that strength to the table as well. (KM)

A key point is how language is used – whether it is used in ways that are inclusive or othering:

When it comes to ‘lived experience’, everyone has lived experience, but it may not be lived experience in this context. For example, everyone is culturally and linguistically diverse. But this has become defined in contrast to mainstream dominant cultures, rather than recognising whiteness as one of the many. So, terms like this can be more othering than about findings solutions together. It’s important to recognise intersectionality and not stereotypes, to be person-centred. All experiences are valid – not preferring one part of diversity over other parts of diversity, just to make sure they are there. (KM)

Expertise and power

There were divergent views within our research team regarding coupling lived experience with terms like experts and expertise, as in ‘lived experience expertise’ and ‘experts by lived experience.’ For some of us, this elevates lived experience to be valued as a form of expertise:

In a research advisory group, I’ve used the term ‘expert-by-experience’ to value the deep knowledge that comes from personal experience, alongside ‘expert-by-profession’ for those holding professional roles. All forms of knowledge have limits and projects where both forms of knowledge are included provide a more well-rounded view. (ACW)

Others in our group are concerned that terms expert or expertise reinforce rather than disrupt hierarchical language. One shouldn’t need to be an expert to create knowledge. “An alternative is to see different forms of knowledge creation and recognise that you don’t need to use the word expert to be an expert.” (AT) One of the problems with the idea of expertise is “the association with

a claim to have arrived or know all that needs to be known on a topic. The point is that learning is a continuing journey. How do you continue that knowledge-development together? How do you recognise you have knowledge in an area, without implying you know everything?" (KM)

Lived experience methodologies are distinguished by their participatory nature. In contrast to traditional research where they are positioned as passive subjects, people with lived experience are recognised as active participants in the research and the research process is seen as generative in and of itself. This means lived experience research can be transformative for both the researcher and research participants as they engage in critical explorations of a topic together. It is therefore useful to locate lived experience research under the umbrella term participatory research.

Lived experience as participatory research

Participatory research (PR) refers to:

research designs, methods, and frameworks that use systematic inquiry in direct collaboration with those affected by the issue being studied for the purpose of action or change. ... Instead of the 'subjects' of traditional research, PR collaborates with stakeholders, community, constituents, and end-users in the research process.²³

These methodologies can be about the decolonising of research, a flip in which "the researched become the researchers"²⁴ while dismantling the structures that have maintained their powerlessness. The inaugural article of the *Journal of Participatory Research Methods* provides a useful table with definitions, variations and key sources on an array of participatory research frameworks and approaches (see Appendix 1).²⁵

Participatory approaches challenge the positivist belief that researchers should be objective and separate from the participants they seek to understand. Instead, this approach to knowledge-creation observes the inescapable subjectivity and generative influence of a researcher. In other words, the process of doing research itself changes the observer and observed. In the 1970s, Brazilian educator Paulo Freire described this as the joining of subjectivity and objectivity "in a dialectical unity producing knowledge in solidarity with action, and vice versa."²⁶

PR seeks to disrupt the power of a traditional researcher. Lived experience research can counteract the "epistemic injustice," a term Miranda Fricker defines as "a wrong done to someone specifically in their capacity as a knower."

Fricker suggests that "testimonial justice" is where the credibility of a speaker's word is directly related to the prejudice of the hearer and "hermeneutical injustice" occurs at a prior stage due to limitations in collective interpretive resources. This results in "an unfair disadvantage to make sense of their social experiences." By embedding or prioritising lived experience research, a knower's credibility has a stronger opportunity to establish an equal standing in knowledge creation.²⁷

Many participatory methodologies including lived experience, co-design and community-led research have core principles and theoretical foundations in critical theory.²⁸ Critical theory critically engages structures and institutions of oppression and seeks political, economic, and cultural transformations.²⁹ While critics of critical theory – including from community organising – rightly focus on its ideological and often reified stances and expectations, we would contend that many of the core principles act as 'guides' from which principles for action can be derived to tackle structural injustices. For example, applying critical theory to education, and influencing participatory methodologies, Paulo Freire drew attention to consciousness of people in marginalised communities. He theorised the critically reflective process of "conscientisation" which means "learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality."³⁰ Influencing much action research and liberating pedagogy, Freire's point is that cultural and systems change must be "forged with, not for, the oppressed."³¹ This participatory, action-oriented approach to research oriented to meaningful change tackling structural injustices is a foundational element of most lived experience research methodologies.³²

Participatory methods value each person "as a person with the right to express themselves and to have the expression valued by others."³³ There is a clear connection with person-centred design and person-centredness, which is also part of the same critical and participatory movement.³⁴ Overarchingly, these methods are about valuing diverse experiences, different forms of knowledge-creation, and involving people in decisions that affect their lives. They are anchored in a reflective process that starts from recognising as researchers we are not separate from our own experiences. Research is not an objective engagement but is a generative process that impacts upon everyone involved.

Lived experience in co-design

The increasing use of the term co-design and its associated methodologies has made it challenging to distinguish whether or not the term has been coopted in such a way that sidesteps meaningful engagement with the original principles of co-design: distribution of power in research, amelioration of the human experience and positive societal impact.³⁵

Across our team of researchers there were divergent views on the term co-design. Some of us preferred the term co-design in relation to lived experience methods, while others did not. There is an attraction linked to the popularity of co-design, which helps bring researchers and participants into projects. However, its application in ways that are not true to the principles of co-design dilutes its meaning. As for alternative terms, 'diverse expertise,' 'expertise from lived experience' and 'community-led' were proposed, noting that none are perfect. Diverse expertise is not clearly something beyond academic expertise. Any use of the terms expert or expertise faces the hierarchical critique above. Some of us like community-led as an umbrella term, while others aren't so sure. Some of us are doing lived experience research but not co-design. While they have much in common, and often overlap, we reiterate that they are two distinct approaches.

The concept of co-design has emerged from design labs, which drew heavily from collaborative research, community development and collaborative action research.³⁶ The "design" element of co-design relates to the use of 'design thinking' to work with 'end users' or communities at the centre of the focus of concern be it design of research, education materials, policies, products or services. The "co" element of co-design refers to the collaborative element of people with lived experiences and communities of diverse experiences being involved in the design process.³⁷ Broadly speaking:

Co-design is a method where community or lived experience participants structure the research from the start – from identifying the research questions to collecting and analysing the data, creating outputs and disseminating findings – so they're involved in the whole project. (AT)

In some contexts, co-design is ubiquitous. In business education, co-design can refer to collaboration between people with different roles including academics, learning designers, curriculum/pedagogy, media producers and students. Health and medicine are leading the way in co-design compared to some other disciplines – they were

"previously whipped for leaving patients out." (AT)
Increasingly, consultation with lived experience is becoming a requirement of grant applications, spurring researchers to consult and develop relationships with lived experience participants. It is also being embedded into human ethics applications with mandatory questions about direct representation from Aboriginal and Torres Strait Islander Peoples. Here, co-design and lived experience engagement are fast becoming the standard practice:

In health services, I think it's welcomed. I think it's going to be part of the norm. I think it's going to be odd if you develop an intervention, and you're not going to involve people from the get-go, I think it's going to be odd if you don't. (MS)

However, this is often done "in a particular box" within clinic trials "either as an implementation piece within a trial, or to meet criteria for participation in a trial." (BM) That is, participation research is nested within a positivist frame and brushing over (and not benefiting from) the emancipatory foundations of co-design itself:

But of course, co-design and trials, in terms of epistemology, completely contradict each other. You're talking about positivism and critical theories. We put it in this kind of box, because it shows that we've engaged with participants and shows we've engaged the community, it shows we've come up with something that stakeholders want. Is that what I consider it to be really about? No. In contrast, you just let it be more free, you have key principles. It's still systematic, but you don't have this kind of linear plan. It shouldn't be linear, but I think we're making it so. (BM)

In policymaking too, there is recognition affected communities should be involved in policy design. However, this often takes the form of a tick-box consultation exercise rather than committing to a participatory process and input of communities. In fact, sometimes co-design is (mis)used as a new term for consultation with citizens and communities.

You can't do public policy work without a commitment to lived experience on paper. But people don't even know why they're doing it. (AT)

Associations with co-design range from consultation and collaboration across silos, through to emancipatory action research that addresses structures of oppression by involving people whom a project is intended to benefit. The popularisation of co-design works for the aim of bringing people into a project and the method, but this popularity

may also be diluting its power and diverting it from its core principles. Many of us are concerned that the language of co-design can be used for consultative practices that are not co-design.

I just find this idea that somehow if you get somebody into a room with you and talk about what you're doing, you're doing co-design. And I think well, no, it's not that. We're talking about deeply embedded engagements over time. We're talking about mutuality. We're talking about working with power relationships. We're talking about ethical behaviours. We're fundamentally talking about care. And we are talking about how we respect people as persons, and the contribution we all must make to something, whatever that is. (BM)

When co-design is used as a synonym for consultation, its true meaning is lost. When engagement with lived experience participants is a tick box exercise, rather than a meaningful process that emancipates communities, it is not co-design. Participants should have an opportunity to provide critique to processes that they have been involved in at a stage where the feedback can be incorporated into final outcomes.

Out of the above discussion, we draw our first foundational principle for participatory research with people of diverse experiences.

Core principle 1

A commitment to critical reflection and ongoing learning at personal and institutional levels.

Questions to consider:

- Thinking of the difference and ambiguous line between lived experience and co-design, what elements and practices define what is and is not co-design?
- In what ways does co-design masquerade as something else?
- Who is the “co” in co-design? Who is the community? Who is included? What parts of which community?
- And how do you move from co-design to co-production, co-dissemination and co-evaluation?
- As all experience is ‘lived’, is ‘first-hand experience’ a better term to use?

2. Power of lived experience in the research process

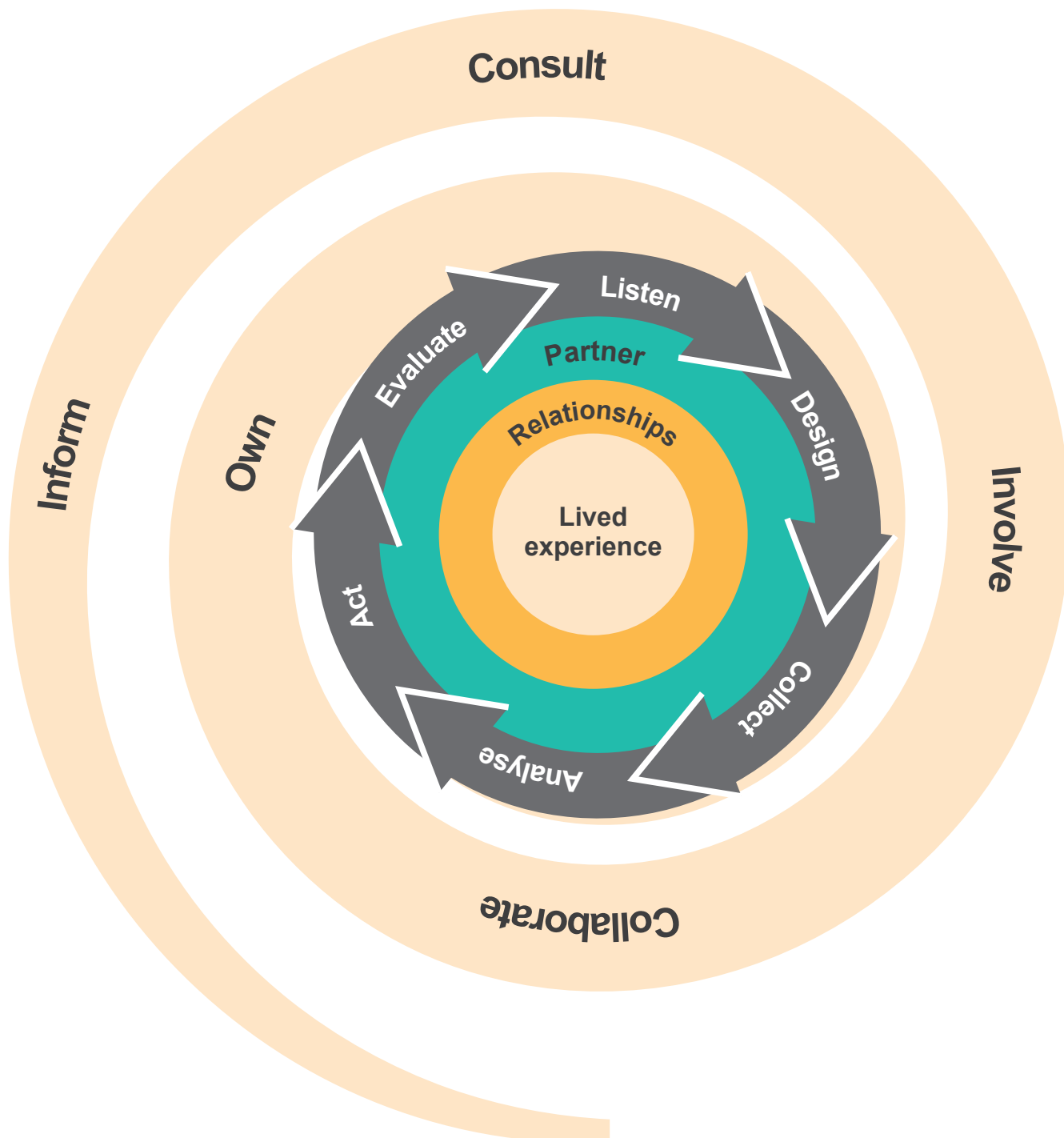


Figure 1. Lived experience participation: a spiral through the iterative research-action processes.

I think there's probably a lot of rhetoric around co-design and power that doesn't match practice. I have my doubts about the level at which power is genuinely shared. (MOC)

Most sociological research attempts to capture people's experiences, using research tools such as surveys, interviews, observation and ethnography. However, these are not all considered lived experience methodologies. A distinguishing factor is recognising the generative and emancipatory nature of research. This means properly considering the experiences of participants, ensuring they benefit from their involvement and their place in owning the knowledge produced.³⁸

Our conversation considered three broad subjects:

1. Conceptualising lived experience in research. Exploring and synthesising research frameworks for lived experience. What is useful to guide thinking?
2. Building and sharing power. The continuum of power sharing and ownership. How are relationships and accountabilities developed?
3. A wellspring of illustrations, techniques and methods. A wide set of examples for lived experience and co-design across disciplines. What does lived experience research look like?

Conceptualising lived experience in research

In exploring the different ways of conceptualising the possibilities for power sharing across the research processes, we reflected on a few of the influential frameworks in participatory methods, adapting them to produce figure 1.

This type of diagram may be a useful tool for reflecting on the different ways lived experience people and communities might be involved at any or all 'stages' of a research process. It brings together aspects of Sherry Arnstein's Ladder of Citizen Participation, The Spectrum of Public Participation by the International Association for Public Participation, Vaughn and Jacquez's Choice Points in the Research Process and the Community Organising Process.³⁹ In discussing these diagrams, some of us found hierarchies of 'levels' to be unhelpful. We wanted to indicate that these 'stages' are not linear, but influence each other in various orders, and are ongoing. We placed 'partner,' 'relationships' and 'lived experience' in the centre of the cycle, reflecting that all of us have lived experience and this impacts our research and how we relate to the lived experiences of the people and communities we work with.

Building and sharing power

In considering how power is expressed and shared in research, lived experience methods assume that latent power is there, and this impacts the questions, language and framing of a project. For example:

It's very common that people think that victim survivors don't have agency, right? They don't resist violence, that's why they're a victim. In contrast is the idea that everyone resists violence, even if they've never been able to leave a relationship. And when you ask the right questions, you will find in their own words, they will tell you how they've resisted violence. (GK)

The deepest engagement is lived experience *leading* and even *owning* the research process. In figure 1 we also add an additional research stage – 'evaluation' – after 'act' and before 'partner.' Conducted together, co-evaluation is a chance for everyone involved to reflect on the goals, progress made in different forms and ways to improve next time round.

Participatory research methods, whether co-design or other, are often tricky and huge learning experiences. It's easy to think of them as neat processes, but the reality is often more messy and difficult. It's why relationships are so important – so you can work through things like power sharing, decision-making, aligning interests, and so on while standing on a firm foundation and commitment to each other. It's also why reflection and evaluation are super important at the end, but really all the way through, so you can check in on friction and readjust rather than let grievances 'fester' and potentially harm the project. I think that's especially important because in contrast to extractive research, community-led research often involves a personal commitment and personal development for participants. Not in a patronising way, but in a really powerful way. These projects aren't just about producing an academic article or policy outputs, but about creating change. And for people personally, participation is transformative in some way and that's what's motivating. Crucial to this is avoiding a transactional view of the project and taking on a more holistic view – that is, seeing relationships and capacity development as valued outcomes, as well as concrete outputs or 'hard' policy changes which are traditionally the 'success criteria.' How to evaluate and value these more 'soft' outcomes isn't quite well-developed yet, and it requires intentionality and processes that allow people to

learn from reflecting on their experience – for example through conversations, interviews, collective debriefs, and collecting anecdotal feedback. (LF)

Lived experience methods allow for authenticity and the power of stories, but it's not without its challenges:

I think the strength is a lived experience participant can call things out with some authenticity and ask questions and keep things real in a way that others might not be able to. They can challenge some of the assumptions and bring the richness of stories that brings things to life. I think the danger is that the responsibility to do all that is foisted onto those people in the process, rather than others stepping up. And the danger that one or a small number of stories are assumed to be representative of stories that they're not representative of as they are one person's experience. (MOC)

Building and sharing power with others has several dimensions. It is produced through relationships, but it also is a product of the strategies used. These practices relate of course, as strategies are chosen by teams of actors through strategic negotiations based on a collective dialogue about power. On top of this, power analysis reveals that questions of scale are relevant as well as lived experience. (AT)⁴⁰

At the most engaged side of the continuum, is leadership and ownership by people with lived experience:

I also think it's important to clearly differentiate between research that is *led by* people with disability and studies which are *co-produced* with people with disability. This differentiation assists to raise awareness about the abilities of individuals with disability to not only contribute to disability research, but also to lead disability studies.⁴¹ This leadership needs to be recognised across all stages of research, from designing the research questions and setting research directions, to collecting and analysing data, to writing up the research, all the way through to widely disseminating research findings. (DM)

Overall, there is a need "to draw on ways in which we ensure that we're giving agency to those participants." (GK)
The benefits of recognising and amplifying a patient's voice was mentioned:

There's an element of also increasing the patient voice. Because they do have a voice. And I do want

to empower them in a system that can be paternalistic. So that's also one of the ultimate objectives. (MS)

This involves seeing the initiative as a partnership:

I think if you go about it with a partnership approach, it becomes less about power and more about establishing a partnership where all stakeholders benefit. (MS)

Co-design can be linked to the three Es of action research: enlightenment, empowerment and emancipation.⁴² It is worth noting:

Too much of co-design goes straight to the empowerment space. But actually, one of the really strong principles of critical social theory is that we have to become enlightened before we can talk about empowerment. And unless you really dig deep into what is this thing we're trying to make sense of, we just end there at the superficial level, if we don't give that enlightenment stage enough time or enough attention, or that kind of real rigor it needs to unpack what is the core issue at play. (BM)

Furthermore, "empowerment" can be contrasted with the idea of "power". That is:

Power means the ability to act, I can't create power for someone else – rather I can support and encourage and teach people how to build power to act. But their actions are theirs not the researcher's, I'm not empowering them – they are exercising power. (AT)

We talk about how we empower people, and it frustrates me, because I have no right to empower anyone. The only person I can empower is myself. All I have a right to do is to create conditions for people to empower themselves. (BM)

Overall, this continuum of methods reflects the extent to which power is being shared and how power imbalances between researchers and participants can remain. For example, advisory group members are often atomised not mobilised:

Too often individuals on research advisory groups are atomised. They're not able to easily push back against the proposals or suggestions that come from the research institution. The best thing they could do is all withdraw. The lack of push back is a function of a lack of power – because they are not

coordinated and because, with the other participants, they haven't had the opportunity to build serious trust with one another. (AT)

Similarly, user groups have a minimal level of participation. An exchange of power cannot be benevolent, it needs to be structural. Most forms of participatory action research are about mobilising processes with people. In contrast, the relational method is about finding already organised lived experience power in community organisations. Community organising has an answer to power imbalances by creating a system of accountability:

In community organising, like in research, you've still got that power imbalance but instead of the researcher, it's the organiser. So the organiser does have power, but it goes: We're going to create a network of leaders from organisations. Those organisations are going to partly or fully fund the organiser, and they are from democratic organisations where there are multiple scales of people involved. ... plus, other leaders know lots and lots of people involved. It is a more sustainable system of organisation and accountability. So the organisations can go, if they don't like what you're doing, "We're withdrawing. We don't like what you're doing. We're staging a revolt." There is a balance of power between the partner organisations and the organisers ... There needs to be a more structural basis for the exchange of power, not benevolence, because otherwise it's not reproducible. (AT)

Union methodologies also challenge power through people with lived experience sharing their stories. This is something developed through training and relational support, as part of unions:

In terms of telling the story, and in terms of advocacy, there's always a member's voice there. That requires structures. It's not just walking into a shopping centre, it's from the structures of the union: workplace delegates, industry committees, people that were identified and invested in over time. So they were the people we would generally hear from, were those that had come to training via an organiser, to build their skills and confidence to tell their story, to voice their position. There would be coaching, briefing and debriefing. It certainly wasn't that people come into this process and then go. It's part of an ongoing relationship with people within the union office that enabled it. (MOC)

The importance of ongoing relationships is a common theme across these methods.

A key to successful policy-relevant participatory or co-design research, is thinking about (a) how do we form a coalition or collaboration and (b) what do we do with it?⁴³ That is, power and tactics.

If you want to influence policy, then you have to also really think about who is part of your coalition, who and what is required for it to have influence. It's important to figure out how you're going to keep that collaboration together and 'in action'. And that's about the collective 'we,' the people or organisations who are involved. It's about committing to a shared goal but also to the way in which you're trying to get to that goal together. I think this intentional investment in relationships, culture and collaborations is a backbone to the work, it's the glue that holds it together. For research to be impactful beyond the academy, researchers may have to go outside their comfort zone – only working with other researchers, only producing research papers, and only thinking about 'translation' isn't going to cut it. So, relationships and diversity can't just be an afterthought. It can't be something that you tack on. It's part of a strategy you have to start much earlier. Who initiates it matters. (LF)

The continuum of power sharing and leadership, at each stage of the research process, is a key variable in distinguishing co-design that is true to its emancipatory roots. A process in which participants collaborate and lead every stage – from partner to design, collect, analyse, disseminate, act and evaluate – would be most faithful to the values and aspirations of co-design. This may not always be achievable or realistic, and that is no reason not to try, nor to give up. Co-design can take very different forms in different contexts. It is an opportunity to be creative, to play, and turn norms upside-down. Researchers can be imaginative about lived experience roles and the nature of that participation throughout the research process.

Learning across narratives

As a group we each reflected on research we had engaged with, including:

- Experts-by-experience coresearchers: Fostering Lifelong Connections (ACW)
- Native Grains collaborative research and Gomeroi Cultural Advisory Committee (KM)
- Owned and run by lived experience: Mad Studies at Queen Margaret University; Writing Group at a

Norwegian Mental Health Institute; and creative methods with older people with dementia (BM)

- Lived experience-led research in disability inclusion (DM)
- Participatory place-based community-led collaboration: The Real Deal (AT)
- Bringing lived experience into research and policymaking: The NSW Refugee Youth Policy Initiative (LF)
- Using community action to co-design resources to empower people with dementia and their carers to engage in medication decisions (MS)
- Co-design in education (EH)
- Finding Voice and Agency (GK)

Just like we can describe power as a tool that has a continuum of practices from “power over,” “power for” or “power with,” research that engages lived experience participants can be conducted in a variety of ways, ranging from extractive “power over” research to collaborative “power with.” For example, only including people with lived experience in data collection, in a one-off workshop, on an advisory committee or as advisors on research translation such as providing feedback on a poster or video, does not necessarily make the experience co-design. This involvement can still be extractive or utilitarian. It is only when conducted in ways that see people as full partners that share power and decision-making, that these approaches become emancipatory. To help with this we identify some foundational values of lived experience methodologies.

Core principle 2

A commitment to sharing power and ensuring lived experience people and communities are involved and in the lead across the research lifecycle, in inclusive and generative ways, wherever possible and on terms decided by those people.

Foundational practices

Some of the foundational practices of lived experience research are:

- Deeply embed engagements over time
- Work with power relationships and evidence that power has been shared
- Mutuality including equal communication on both sides and allowances to respond to feedback, such as time considerations
- Be open to other ideas and frameworks
- Include and recognise lived experience contributors as authors
- Evaluate based on the purpose and success of research, with the goal being to learn and to improve practical impact that helps improve the lives of people
- Encourage participation at the person’s discretion, e.g. leading the study if they want to
- Sufficiently fund and allocate time for accommodations and mentoring and development if desired or required
- Conduct all research in an inclusive way
- Consistently value and respect the voices of lived experience
- Provide opportunities to disclose social location such as having a disability, e.g. in a publication
- Start co-design as early as you can, don’t let it be an afterthought
- Be authentic and pay attention to the process of doing it rather than the outcomes of just doing it
- Build relationships where people get to know one another first, respecting people as persons and acknowledging the contribution we all have to make
- Recognising that a research culture and a community culture (and different community cultures) can be really different – and finding time to negotiate expectations and needs

3. Challenges and practical considerations

You can't just go on the street and pick a person with lived experience and drop them into a project. But you also can't let yourself be stopped by it needing to be perfect. (LF)

Sometimes it's just about strategic choice. I don't know how to run that Mad Studies method on The Real Deal project. It would flop because it's just too hard. Maybe that's me giving up but it's just I couldn't imagine about how to do it. So there's a strategic choice about how to manage a project with scale, resources, power. It's slightly different to the lead model, but there's ways through that are all following certain themes and concepts. (AT)

One may understand the principles, know the methods and have the best of intentions to do genuine co-design with people and communities of diverse experiences. However, they might not know where to start, fearful of getting it wrong, not sure how to find people to be involved, how to compensate and acknowledge them, how to engage in culturally responsive ways, and how to ensure one is not tokenistic in the engagement. Here we discuss key institutional and cultural challenges and address some practical considerations surrounding lived experience inclusion.

Our conversations surfaced three themes in terms of the practicalities of engaging in lived experience research:

1. Institutional barriers to lived experience research. Universities have been established to support traditional research. What institutional challenges get in the way of lived experience research and how can these be overcome?
2. Cultural changes in doing lived experience research. The value of lived experience research is becoming recognised but there are barriers. What are the shifts in cultures and mindsets needed to support this research?
3. Practical considerations. The pre-work including recruitment, relationship building and consideration of benefits. What are the practical steps for researchers to undertake lived experience research?

Institutional barriers to lived experience research

Major institutional barriers to lived experience research include time, ethics, capacity building (on both sides) and

employment processes. These make it challenging for researchers to do authentic co-design and lived experience research. Yet there are opportunities for universities, funders and academic journals to help overcome these barriers.

Time

Lived experience research takes time. It can be slower and there are initially fewer academic outputs, so it inadvertently disincentivised by universities and career development paths for researchers. This is both because non-academic outputs such as community reports, media pieces and policy briefs are prioritised, and because each stage of the research and publication process takes time to involve lived experience participants.

The major thing is the time it takes. That's the number one. (MOC)

Co-produced and lived experience-led research remains largely undervalued in academic performance metrics.⁴⁴ (DM)

Co-design requires extra time and extra planning, it kicks out timelines and budget. (LF)

Ethics

Ethics applications within universities can sometimes be challenging, as they remain predominantly in a positivist framework and have a limited number of lived experience researchers on committees. Researchers face a chicken and egg scenario, needing ethics clearance before engaging communities, while needing relationships to be developed prior to devising the research design:

For ethics, you need to have a research question and then go to the community. But co-design says: Go to the community, and then get the research questions, right? So they don't talk to each other very well. (AT)

Ethics applications can also take extra time, requiring additional explanation about lived experience and co-design approaches, and the flexibility that this approach entails. Sometimes the protective role of the ethics committee can limit agency of people to participate. For example:

We have trouble with the inclusion of students, because the ethics committee are very concerned about that sort of coercion and status power imbalance between students feeling coerced into taking part. In reality, we put a notice out there, and we have hundreds of students say, 'I'd like to be part of this.' We don't have any issues, and you know if you felt coerced or you didn't want to, you just wouldn't be a part of it. (EH)

Furthermore, ethics committees can, out of concern, make it near-impossible to work with some marginalised and highly traumatised populations:

I know there's a lot of concern, certainly in the areas that I work, in that ethics committees' approach silences lived experience, because people are held to be too fragile to participate. So it's very hard for them to even be participants. (GK)

Opportunities exist to reframe vulnerability in a way that does not overstate the risks of including researchers with disability in accommodating settings. Lessons from the pandemic include that ultimately, we as humans are all susceptible to harm.

Designing ethics as a staged approach is one way to enable research that is more iterative. The overall aims of the research can be described, with data collection for the first stage specified and submitting additional applications for the subsequent stages as they are developed through the co-design process, noting that this can be a time-consuming process.

Employment

Employment and HR processes can also be inhibitive, with an ethical requirement to pay lived experience advisors:

No system of payment that works. I just do vouchers at the moment ... I can't employ her, I'd love to, but I don't know how. (Co-author)

If you hire a lived experience researcher, they've got to do the same training models done by a full-time campus researcher, which means that they are doing a lot of training that isn't very relevant. For some, this is annoying. But for people with limited time or other social pressures, these kinds of unthinking demands can and have encouraged people to not become lived experience researchers. While a group of us on campus (the co-design working group) have created a workaround, unless you know us, you won't know the workaround. It needs to be better. (AT)

A suggestion to get around this is to create a new employment status for lived experience researcher within university systems, akin to voluntary positions. This way the role is acknowledged properly, can be paid, have status, be protected, and IP shared.⁴⁵

Promotion and Research Skills

To improve a recognition of lived experience and co-design research skills in academic professional development and promotion, there could be a formal recognition and weighting given to community engagement in our research role beyond in governance and leadership. It would also be useful for non-traditional outputs to be relevant to research promotion, and greater investments and more formal recognition of alternative career pathways such as researcher development pathways, professors of practice, fellowships and dedicated lived experience researcher positions. Furthermore, there's a need to recognise and value lived experience in recruitment processes. (AT)

Sharing knowledge in research agreements

There's also the issue of who has access to and "owns" the research IP. The importance and recognition of cultural knowledge is well-established in the University. But our research and partner agreements have a standard clause that is used for participatory and lived experience research, where the University "owns" knowledge rather than sharing it with research partner.

Research agreements say that all the knowledge is ours. It's not shared. There's no global license to share it. (AT)

It is possible for researchers to amend specific clauses in research agreements, however this can be time consuming – delaying the progress of research with communities who, ironically, often lament how slow university processes are. These are often also confidential and such clauses are not always possible or able to be agreed for other reasons.

Funding

Then there are the funding bodies, who need to better value lived experience in research proposal assessment criteria:

Research teams need to explain how they are including, accommodating and properly compensating researchers with lived experience in their disability research funding proposals. (DM)

Funding also needs to ensure that the accessibility and accommodation requirements of researchers with disability are met, again on an individual basis. (DM)

Moreover, funding for lived experience research often is more available from non-traditional sources such as not-for-profits, philanthropy and industry. Greater training in how to build these kinds of funding relationships is needed for funding like this to be easier to access.

Overcoming barriers

The grant calls and targeted schemes are helping to promote lived experience research methods in health and medicine. These elements could be added to grant opportunities in other fields too:

... pushing that agenda, like, who are your partners in research? And I think that's going to change how we do things. (MS)

There is a dedicated Discovery Indigenous Grant round but not within other schemes. It would also be good to educate governments doing or funding research on ethical approaches to lived experience research and develop best practice ethical frameworks for lived experience research conducted outside universities.

Academic journals should give authors the opportunity to disclose lived experiences:

Disability journals need to give authors who want to disclose having a disability the opportunity to do so. (DM)

To be genuinely inclusive, this approach starts at the outset, and involves economic incentives and quotas to make it happen:

Academies that include lived experience in their titles need to be genuinely inclusive of researchers with disability at the outset. To do otherwise is to risk being tokenistic and ableist. (DM)

If we're saying for disability research that we want to increase the participation rates of researchers with disability, funding assessment schemes should have criteria which factors in the lived experience representations into proposals. So that way, you are guaranteeing that inclusion and there's an economic incentive to be included. (DM)

Cultural challenges in doing lived experience research

Lived experience and co-design approaches lead to better policy outcomes for communities involved. However, lived experience research is often not understood or valued in communities or by government. There is a general

resistance and pull to continue business as usual. There is also a cultural valuing of quantitative over qualitative research when it comes to interpreting what is evidence-based research:

Broadly in the community, people always say, 'Oh, so you only interviewed 20 or 30 women, so what can that tell you?' Explaining the nature of what qualitative research is, and how we validate that through other methodologies has been a challenge as well. ... It's as if it's not statistically valid, which it's not – it's not quantitative. We're not talking about statistics. As if it's less, the research is less valuable. (GK)

Policy also focuses on statistics, so there is a need to link lived experience research with statistics to speak to policy questions:

I usually don't dabble in statistical analysis. But I think speaking to policy questions, we've got to do that. (GK)

Having people with experience doing co-design is important for all involved. Experienced facilitators, for instance, can make all the difference, like when it is necessary to call out bad behaviour and power involved, even if it comes from people with lived experience.

I'm not sure we really prepare people enough. That's why I worry sometimes about people wandering into co-design, if they don't have the facilitation skills to manage those really complex situations. (BM)

There is also an issue of academic culture and practice, which can be exclusive and work against the aims of co-design and sharing power:

Academic cultures and practices which are impenetrable and alienating – a kind of assumed and taken for granted and not questioned – that really excludes people and entrenches power. Some of the little things like the titles that people have – associate professors and lecturers and all of these layers. I still don't understand them all. It's like a barrage that pushes one back. There's a lack of use of plain English. Like a particular vocabulary implies a sophistication of thinking, which I totally reject. And yet, we use language that is impenetrable for a very switched-on smart layperson. And it can feel deliberate. It feels like a barrage of 'Oh, that's right. I'm not really from this world and I haven't got anything to add,' which is not actually the case. But I think it can feel that way. (MOC)

For example, ableism – disability discrimination – is a major barrier to a greater representation of lived experience-led and research co-produced with people with disability.⁴⁶ Part of this might be resistance, because people do not want to give away power:

Some non-disabled people might resist inclusive language and actions to support their positions of power and prestige as researchers or as policymakers. In this light, non-disabled policy professionals can often be unwilling to include people with lived experience as co-workers.⁴⁷ (DM)

It is important to make sure the language of lived experience and co-design does not become diluted:

It's therefore important that language around disability inclusion in research and policymaking activities does not become diluted by those who fear a loss of power from any change in an unfair status quo. (DM)

This speaks to a broader cultural shift to see the value of qualitative methods, bringing vital and distinctive evidence-based knowledge compared to that of quantitative approaches.

Practical considerations

I think there's curiosity about co-design and lived experience, but I think there's a lack of skill around in relation to making it happen. (BM)

When doing community-led research with teams of community and academic coresearchers, there can be a tendency to huddle. This can be overcome by recognising communities, meeting in these huddles, conducting one-on-ones, and coming together as a research group.

Recruitment: How to find people of diverse experiences

One of the first steps to good co-design is recruiting participants in such a way that is ethical, fits in the timeframe of a project and also avoids tokenism. Where do you start? A key to this is, once again, is relationships and power:

Spend time to genuinely build relationships and trust. Keep showing up in authentic ways. Build psychological and cultural safety when things can be called out. Be responsive to change and do things differently. If you don't have a diverse workforce, you can't do it. You need to go beyond one representative of a community. (KM)

Avoiding tokenism is about being authentic, seeing it as partnership, working with our power, being reflexive, and constantly pushing on the continuum of participation discussed above. It is about seeing the multidimensionality of a person, not treating a person in ways that reduce them to one aspect of their personhood.

Need a balance between respecting every lived experience story while not generalising from a small number of stories. Avoid tokenism by triangulating data: validate core views by triangulating them with interviews from others e.g. women through a divorce process and professionals that support them. So this isn't just one person saying or 20 people saying it, right, this is actually supported by another 30 professionals who each have supported countless women. (GK)

Participation must be voluntary, but sometimes that leaves out the target groups. For example:

You want to find out why students are not engaging in class, but only engaged students will put up their hands for the research, while the people with the problems who you want to involve and understand probably don't have the time to get involved. (EH)

That said, how you engage identified communities matters.

A relational method approach doesn't send out a call for people to participate in research but goes to those target and identified communities and seeks to build relationships as a way to explore engagement in research. (AT)

One approach to recruitment is through a Lived Experience Advisory Panel – present your research and put out an open call for involvement:

I presented my proposal to Lived Experience Expert Advisory Panel of Sydney Dementia Network. They provided really good, valuable feedback and then they said, "If anyone's interested to provide more feedback, then they can contact you by email." So I gave my email to the organisers and then my lived experience person contacted me. We've had an amazing relationship. I've been engaged with her constantly in my research projects, and yeah, I don't think I'm going to do research any other way from now. (MS)

Another way to find participants is through structured organisations such as peak bodies, advocacy groups, alliances and unions. It is also important that the people

selected to participate together go through a formation process:

The deliberate way in which groups are enabled to go through a formation process is really important, so that relationships can be built and imbalances in power can be at the very least acknowledged. (MOC)

Considering the intersectionality of lived experience participants who are recruited allows for multiple layers of understandings to be brought to a project. For example:

A woman that we have on our advisory group for Australia Cares is a care worker, but she's also an experienced union member who's on an industry committee within her union and has a vision beyond her own experience of her everyday going to work for a disability provider. (MOC)

Another approach is to use a power analysis, which is to map people and organisations according to their influence and alignment with your cause. From here, select participants strategically in order to further the cause.

Both from a perspective of building power as well as legitimacy, it can be important and effective to work with organisations that are connected to the first-hand experiences through their membership. However, it's also about the quality and depth of the connections and relationships an organisation has to its members or 'the grassroots' with lived experience. Sometimes being 'professionalised' means organisations have actually come to operate at a distance from the people they supposedly exist for. A good question to ask is what role their members have in the organisation – what does that relationship look like? Do they have a say? Are they involved in setting vision or strategy somehow? And then it's about ensuring not to fall into a transactional or short-term approach, but about being genuine about trying to build a relationship, and figuring out how collaboration connects to their purpose and their ability to deliver on it. It takes effort to develop those relationships. You can't delegate or determine how and when they engage, that's about their appetite and negotiation around your shared interest. (LF)

While the process of selecting lived experience participants is important, the point in the research process that people are invited into these processes is also crucial:

If it's at the point where a whole bunch of key decisions have been made and they're there for

colour and movement, well, that's not cool. But if you're there in the inception, the framing, the decision making, then that's a different thing. (MOC)

Preparation for co-design

As Lynette Riley argues in her book chapter *Community-Led Research through an Aboriginal Lens*, lot of pre-work goes into making sure that you level the playing field at the start of a co-design process.⁴⁸

There's a lot of pre-work, before we get into the co-design of the thing that we're focused on. There's work to do on shared values and getting to know each other as persons, what we're bringing to the space, who we are, what we're about, what that shared experience is that we all want to contribute to. I think we have to really facilitate engagement and discussion about that before we get stuck into designing anything. We have to create safe spaces for brave conversations, to have dialogue that isn't always action orientated, but is about surfacing and venting, and giving voice. It's not just about results and outcomes, it's about creating that safe space and enabling our own positionality to be made explicit. (BM)

It is important to set clear expectations from the beginning, and establish a co-design term of reference:

We kick off with a "Connect:In" workshop with all of the different stakeholder groups: students, the alumni, tutors, unit coordinators, media and educational and academics. Together we set some sort of loose guidelines and discuss expectations – get it all out on the table and have a good chat about it before we begin, so we people can ask questions that don't feel silly. We include an expectation to be fluid in terms of you know what might happen, what direction you might take, because there are so many stakeholders involved. Then we separate into different groups to do the work. You can't have everybody all the time in every single meeting. So then you sort of peel away some of the layers, you might have a core group, which is usually the unit coordinator and the educational developer. (EH)

One way to approach this pre-work is to use a series of workshops with the same groups or subgroups of people, ideally with one-on-one conversations – relational meetings – before and between sessions. Sometimes this involves subgroups who convene, do research and develop a draft position paper which they report back to the main group. It also involves ensuring that engagements are done in ethical, inclusive and in culturally safe ways:

Issues around inclusion, around time of day, place of meeting, availability of childcare, providing people with meals or safe ways to get home if it's at night. There's pay – who's on paid time and who's not? How do you deal with all those things. I think that's really critical. (MOC)

While there are still many gaps when it comes to the inclusion of people with lived experience and in recording these inclusions, more people are doing lived experience research including private institutions, advocacy organisations and government researchers. But when lived experience research is conducted outside of universities it often lacks ethics committees and approval processes.

There are multiple ethical considerations surrounding collecting, analysing and publishing the data:

Within the lived experience methodology, safeguards are built into it, so that we're not just using lived experience for the sake of data. We're actually being really careful with those participants to have that recognised. (GK)

This means really acknowledging a person's lived experience in a methodology and thinking deeply about the way an interview is conducted and the ways a person's stories are or are not (re)told:

I guess it's recognising the role of the researcher or the interviewer as an ongoing reflexive process. Language used within interviews is therefore important too. For example, by focusing agency and acts of resistance of victim survivors, this impacts questions asked, and has a flow on to analysis and publication. Unless you asked in that particular way, you're not going to identify that as being an act of resistance. So your methods of interviewing will impact the data that you get, which will inevitably have a flow on to the analysis and what you publish. (GK)

Community or corporate advocacy could accidentally use a person's story unethically, to enable government buy in:

They would relay those lived experience in order to capture, for example, government's attention, or to draw on case studies or videos. And that has a role to play. But I don't think they've thought through ethically all those requirements. The point is these are people's lives. This is not a made-up hypothetical scenario, even when you de-identify it. That is someone's life and someone's story that they've

shared with you. So I think we have to be careful over that as well. (GK)

Ongoing communication is very important. For example, writing short quarterly reports that are a lay summary of outcomes and changes resulting from collaboration. By showing the results of what has been done, people will be keen to get involved again.

Create spaces to play, be creative and think differently:

For me, it's about creativity and using different ways to give voice, because it's not just about talking. It's just about ways of being and how we help people to express themselves in different ways that draw on different worldviews and different sources of knowledge that balances out power. One of the greatest things about creativity is it's a real leveller of power imbalances, because it's not about what you know, it's just about engagement in doing something together as committed partners. (BM)

Benefits through payment, recognition and impact

The most important thing is the practical impact that a research paper has in terms of helping to improve the lives of people with disability. (DM)

Overall, there's a need to prioritise benefits to participants, community and priority populations through financial compensation, shared authorship, mentoring, capacity building and enabling ongoing relationships on their terms. For one, the process of storytelling can be empowering itself:

I've learned that every individual has the power through their own words. (GK)

As an example, educational co-design with students benefits both teachers and students:

Insights from the coal face for example, as students, are different to insights from the literature and teaching side. This leads to benefits in the way teaching is delivered, or the length of time that we have them in a room. For example, students sustain their interest and engagement for an hour and a half, or is it better to keep it to 45 minutes? So you know there's lots of things that someone who's living through the experience can tell you. (EH)

There are multifold advantages of lived experience-led research in disability:

There are many benefits of research about disability that is led by or co-created with people with disability. These advantages include empowering people with disability in setting research directions that can tackle challenging policy issues, helping to reduce disability stigma and ableism, and designing research methods that are empathetic to the needs of study participants with disability. I also note the tremendous potential of lived experience leadership academies to develop people with disability as leaders of disability research.⁴⁹ (DM)

In most contexts, there is a need for financial compensation that appreciates the value of people's time and contribution, and recognition through authorship.

I do believe that everyone should be compensated for their work. I don't think buying a bottle of wine is acceptable for when you've given days of effort. And actually, this is why the UK is ahead of Australia on this. There are some really strong guidelines in the UK that everyone works with around participation and research with people who have lived experience.⁵⁰ Researchers are required to show the involvement of 'lay participants' in all stages of the research, including how they are being recompensed, which has got to be costed into the research grant. (BM)

Participants need to be commensurately paid:

Too often, researchers with disability are not paid at all or are given t-shirts or vouchers that do not come close to adequately compensating them for their time and other research expenses, e.g. travel, carers, accessibility requirements, and so on. Investments are needed in developing career pathways, e.g. disability research fellowships and dedicated lived experience researcher positions, so that researchers with disability are not exploited and left languishing in unpaid roles or are left out entirely. (DM)

Aboriginal and Torres Strait Islander people are constantly being offered 'exposure' in lieu of payment. Context is also highly important. Our communities have long histories of stolen wages, stolen knowledges and the exclusion of economic participation. Therefore, it is important that conversations around reciprocity are maintained. (KM)

When lived experience researchers are hired as part of the research team, their time is compensated like

other researchers, they put in a timesheet and that is a signal of value. (ACW)

This means the cost of payment must be factored into grant applications from the beginning:

Payment is important. You need to pay participants for their time, so it's important to build participants' payments into their grant application at the beginning. Also catering for participants is important to get funding for. (EH)

A consideration regarding payment, where "too much is questionable and can alter the research." (GK) There's a consensus payment must *remove barriers* to participation, and that *reimbursements for expenses* are important:

When it comes to payment, you're making it possible in whatever way to take away barriers to full participation. You need to ask "What support do you need to fully engage? How do we make sure you feel able and safe to fully engage at your discretion?" That can look like payment for their time and trouble, but in addition it can also involve reimbursement of childcare expenses, paying for travel and accommodation, ensuring a carer can accompany them, you name it. (LF)

If I usually earn 500 bucks a day and I'm giving up half a day or a day to participate in this, I should get what I usually get for that for my day. The danger with giving people more than that is that it colours motivation. If it's a small community organisation and this is a cost on their resources, that should be considered. An arbitrary number – "Oh, yeah. 100 bucks" – doesn't sit well. I think it needs to be pegged to something like what some consumer groups are doing or what people get jury duty sessions or sessions of government inquiries. (MOC)

Those of us coming from the community organising tradition noted the need also to have space for volunteering and valuing unpaid work.

In community organising, it's different. What you're doing is contributing to an organising effort that you and your community are the beneficiaries of, as opposed to volunteering for someone's research that they take off and write, and gives them credit towards their academic future. (MOC)

We are democratic citizens, and it's actually okay, I volunteer all the time. When the scale of people who are involved becomes large – I couldn't do it if I paid

everyone. Where communities are benefiting from the process, that might need to suffice. (AT)

In this context, the question is then:

How much time is someone putting in? More than a couple of hours a week of analysis or data collection – sounds like a research role so you should look to pay that person. People are going to have to do some volunteer work, but it's their community being benefited, and they're putting in the time to make their community better. They're not doing it for me. I'm not paying them for that. They're doing it for themselves. They're helping themselves, and you're helping them help themselves, and therefore it's a great relationship. (AT)

There was also agreement that co-authorship is important:

Those who help shape the design, shape the research question and the proposal when it comes to ethics, are given them the option to be co-author. (MS)

There also needs to be a requirement that people with disability are included as authors in any research publications that they have contributed to. No exceptions! (DM)

Lived experience research makes researchers question assumptions and unconscious biases in surprising ways:

You're always trying to learn something you will never find out by reading people's secondary thoughts about it or commentary on it. I work a lot with cultural and linguistically diverse communities. Being aware of how to interview people and the nuances of those communities has been challenging, even though I often share their background. From an interviewer perspective, it means leaving those assumptions at the door. There's a lot to learn and unlearn in that process, and does require some conscious methodology. (GK)

I was interviewing in the space of imams in the Muslim community, and we're talking about issues to do with women and I just thought, yeah, okay, I've interviewed enough, I know what's going to come my way. I was so blown away by this person that I interviewed, we were in his living room, and he broke down crying, talking about what he saw as the difficulties that women faced in the community. ... And then I interviewed a female lawyer who was supporting women who are going through divorce.

And I thought, I know generally what you know what that's going to be. And it was the exact opposite. It was basically that women make up stories, and men are the ones that are hard done by. And the end of that day, I was just like, well there you go, that's why we do the research, because you actually cannot make assumptions. The interview with the Imam gave me such a richer data set about imams' perspectives, and it changed the nature of the research because of the way in which I was then framing questions. And so I was checking in with my own biases and assumptions that I had made in doing the interviews. The interview flipped it the other way. (GK)

Overall, the biggest challenge is time. It takes time to build trust and not everyone has that time available. Co-design is new for a lot of people and there's a need to manage expectations upfront. It's important to be clear on aims:

In your first interaction, you got to be clear on your aims, expectations and what their role is going to be. And then clear communication throughout. Give them options. And then acknowledgement. Whether it's through authorship or investment. And I think just building developing trust over time. (MS)

Co-design and lived experience-led research helps researchers collect better data and do better research, with a greater power to influence policy as it has the backing of community and often the involvement of policymakers in the research process. So, it's not separating community from research from policy, but bringing all three together and sharing new perspectives.

Core principle 3

A commitment to involving the cultures and institutions engaged in this work to properly and ethically value, respect and benefit people and communities of diverse lived experiences in long-lasting ways.

Closing reflections

There is no formula for lived experience research. Recognising and building knowledge centred on people's lived experience needs can be emancipatory. For that to happen, it looks different to different people. Participation and interaction need to be generative and imaginative. Thus, rather than a rigid or prescriptive guide, the core principles and practices developed in this report are offered as a guiding starting point for play. Continuous evaluation is crucial to engender a culture of learning and shaping the involvement of people with lived experience throughout stages of the research process. For this reason, we placed co-evaluation inside the cyclical research process in figure 1. Here we recap the core principles and values, and our closing reflections and questions that we are curious to explore in future research.

Core principle 1

Lived experience research requires researchers to question values and assumptions, be open to changing research direction, and learn from the people and communities one is working with.

This includes researchers with lived experience of the topic under investigation, with and without research qualifications. Lived experience methodologies start with a process of critical reflection of the position – sometimes called 'positionality' – of those who are initiating the research or policy initiative. This means being aware of our own power and social position of the historical and cultural context from which our privilege as, for example, researchers at the University of Sydney have come from. It means being aware of those who have not benefited from those historical circumstances. It means being aware of the types of skills and types of knowledges that have been cultivated and privileged within a western capitalist society. It means recognising the ableism and stigma that overlooks the abilities of people with lived experience of disability. It means being aware of the ongoing impacts of racism, colonialism and imperialism. It means recognising the ongoing injustices that Aboriginal and Torres Strait Islander people face, the horrific impacts of white Australian policies that have denied Indigenous people their culture, languages and ways of knowing. It means recognising the Country on which we work and the ways in which our lives are entangled in the wellbeing of the ecosystems of which we are a part. It means recognising the destruction that patriarchy has caused and its ongoing impact on hidden our values and assumptions. This is the context in which we live and do our research, and we participate in the continuing evolution of this culture and context. The first principle of lived experience research is a call for continuous critical self-reflection, learning and improvement.

Core principle 2

Doing lived experience research calls us to consider how people with lived experience of the topic are being included throughout the research or design process.

This means including people with lived experience from as early as possible and being willing and open to changing the framing, particularly the research question, as led by those people or communities. They are the closest to the topic of concern and their knowledge is to be privileged. There are many ways to do this. Our report shared some of these methods, not in an exhaustive way but drawing from our own experiences we illustrate some of the ways that this may be done. For example, consulting lived experience advisory panels, lived experience advisors, power analysis and relationships, co-researchers, co-designers and lived experience-led research.

Core principle 3

Including lived experience requires investing additional time and money in relationships with the people and communities in authentic and reciprocal ways, and avoiding tokenistic, extractive and exclusive approaches.

Its priority is to benefit people and communities through the process of their involvement and from the research outcomes. Thus, the third and final core principle we articulated was a commitment to continually evolving the cultures and institutions to properly and ethically value, respect and benefit people and communities of diverse lived experiences in long-lasting ways. This includes a commitment to challenging systems and structures that perpetuate injustice.

Opportunities for future work identified by our research team include:

1. interviewing people with lived experience who are involved in research, and understand the ways in which they can be better supported
2. initiating a piece of action research that seeks to change institutional barriers by interviewing people in government and Head of Schools, people who set the grant questions and set the agenda, encouraging and educating government to care about ethical methodologies being used
3. collecting evidence of co-design producing better policy
4. developing or sharing existing good or best practice frameworks in different subject areas.

This is the start of a conversation with other researchers and university leaders across disciplines and faculties, and most importantly with lived experience people and communities. Starting is often where one can get stuck, and we hope that this report's wellspring of examples and discussion between authors across disciplines has provided a strong sense of the variety of methods and approaches that can be applied in this space. We encourage researchers to play with the possibilities of involving lived experience people and communities no matter what stage they may be at. With this in mind, we close the report by addressing perhaps the most common question: "Where should I start?" In response, we share some reflections on the ways that some of us start our lived experience work.

Starting example 1

Start with shared values (BM)

For me lived experience work always starts from a position of developing shared values for our engagement, our ways of working and our expectations of each other. Shared values act as a kind of anchor to return to as the work progresses. They help to reorientate us as collaborators when processes might run off course, when complexities arise that have the potential to surface conflicts and, indeed, they are a useful tool for guiding how conflicts are managed. Most importantly though, shared values help us foster authentic engagements that are not ego driven. I am drawn to the work of Callaghan.

One of the difficulties in dealing with anything related to human experience is caused by no two people being exactly alike. There is so much that we have in common that we are inclined to imagine everyone is the same. Everybody is not. That which has meaning for one person may have none for another. Something of immense significance for one will mean little or nothing to another. The basic axiom is that each person is an individual and as such, a unique entity. This must never be forgotten in our attempts at self-awareness or in our dealings with others.⁵¹

This quote resonates with my thinking that in our research we need to create the conditions for everyone has the potential to flourish – we flourish as persons when we bound and frame our co-existing energies, when we embrace the known and yet to be known, when we embody contrasts and when we achieve stillness and harmony. When we flourish, we give and receive loving kindness.

Starting example 2

Start with honest communication (DM)

As a neurodivergent researcher, the starting point for research projects that I have led or co-led share is about setting a foundation of open and honest communication. I begin by talking with researchers with disability (with and without research qualifications), members of disability communities and genuine non-disabled allies about a broad topic of research interest. I also ensure that any accommodations which are needed to allow these conversations to take place are included at the outset (and not forgotten about as the project proceeds).

Following initial conversations about where the research is broadly heading, targeted research questions are then collaboratively developed. Respectful conversations continue until general agreement among team members about the specific research direction is reached. Moving forward, the study design is again put together in a collaborative way. Key to achieving inclusive research design is to have researchers with lived experience of disability feeling comfortable to ask for any accommodations that they might need to participate in data collection and analysis activities or in any other part of the project. By openly discussing my neurodivergence and related accommodation needs, I send a message to all other team members that they are in a safe and inclusive research environment.

Starting example 3

Start with reflective dialogue (ACW)

Conducting research on child protection and out-of-home care is very sensitive and those with lived experience have typically experienced trauma, grief and loss. Many people who have gone through these experiences are passionate about changing practice so that other children and families have a better experience. For the ARC Linkage *Fostering Lifelong Connections* project, our research team recruited co-researchers through our networks with out-of-home care organisations. Those who expressed interest and worked with us as co-researchers had often had a role as an advocate or trainer, in which they had already used their lived experience for social change.

As a starting point for the project, we established space for dialogue and reflective practice. It took time to build trust and rapport that allowed for critical discussions about the research. Through our discussions, we jointly decided what would be the focus of collaboration. Co-researchers made contributions that drew upon their talents, including illustration, graphic design and writing, making lasting individual and collective contributions to the project.

Starting example 4

Start with a personal education on the communities that live in your place of focus (KM)

Do not expect others to educate you, but take a personal commitment to starting that work yourself. Do not ask of others what you can Google yourself. Everyone is on a cultural journey, even some Aboriginal and Torres Strait Islander people are actively reclaiming knowledge and culture. While some communities may have greater access to knowledge and stories in the public domain, be respectful, start slow and build relationships with what is available to you.

Demonstrate value, show up to community events, where invited. Many Aboriginal and Torres Strait Islander organisations are under resourced and over committed. Where possible, try to take a detailed assessment of what has come before you. Listen, learn and give back where you can.

Starting example 5

Start with relationships and power (AT)

I seek to bring two somewhat contradictory practices and principles to bear on any collaborative research question. The first is deep relational practice, where I seek to start not with data but with people, invoking the quality of curiosity and wonder. I also seek to pair that soft practice with a harder analytical analysis of power, being attuned to who I am meeting with and ensuring that the network of relationships that is being cultivated has the capacity to not only be creative but to create impact. Power in this sense isn't the ability to dominate or decide, but the capacity to act – and it is a capacity that is generated and produced in relationship with others. Relational power is about creating networks that are diverse and surprising, where learning and change is possible, where uncertainty can help produce new knowledge.

I like to talk about this kind of practice as a "tortoise method" – where you go slow to eventually move fast, because the right trust and spaces have been created for lasting transformational knowledge and impact.

Appendix 1. Participatory research frameworks, orientations, and approaches

The table below has been reproduced with permission from L. M. Vaughn and F. Jacquez, and the Journal of Participatory Research Methods.⁵² The authors of this report have added Co-Design, Lived Experience Research, Relational Method and Community-Led Research, and also expanded Decolonising Methodologies to Indigenous Research Methodologies.

Framework/Approach	Definition	Types/Variations
Action Anthropology	A process of social science research that combines inquiry with practical solutions of day-to-day problems of a particular group or community.	applied action anthropology; collective action anthropology
Action Inquiry	An approach to learning and inquiry that combines research and practice for the purpose of transformational change; often applied to leadership practices.	cooperative inquiry; dialectical inquiry
Action Learning	A problem-solving approach that uses a process of action and reflection. Commonly used in businesses and non-profits and in governmental and educational settings.	action reflection learning; critical action learning; unlearning
Action Research (AR)	Represents a broad family of research approaches that emphasize social change and transformation, active collaboration through participation between researcher and members of the system, and iterative cycles of action and reflection to address practical concerns.	arts-based AR; critical AR; feminist AR; first person AR; systematic AR
Action Science	An intervention approach used within organization development to improve behavioural processes and organizational effectiveness, encourage learning, and create interpersonal, group, intergroup, or organization-wide change.	organization development
Appreciative Inquiry (AI)	An asset-based approach based in the positive potential of individuals, communities, and organizations that directly engages stakeholders in positive social change around what is already working rather than solving problems.	appreciative systems
Asset-Based Community Development (ABCD)	An approach to sustainable community-driven development that posits communities can drive the development process themselves by identifying and mobilizing existing, but often unrecognized assets.	citizen-led development
Citizen Science	Research that is conducted at least in some degree by members of the public; popularized in environmental science	public participation in science; crowd-sourced science; civic science

Framework/Approach	Definition	Types/Variations
Co-design	Research that works with people directly impacted by decisions and whose lived-experience can helpfully shape practical solutions. Co-design is not a single method, but reflects the use of a variety of engagement methods with individuals and groups. Co-design takes time, creativity and a commitment to ongoing partnership working for effective and impactful outcomes.	coproduction
Collaborative Change Research, Evaluation, & Design (CCRED)	Collective term referring to participatory approaches utilized by researchers, evaluators and designers who bridge research and practice for positive social change	collaborative change research
Community-Based Participatory Research (CBPR)	An orientation to research often focused on health-related issues that equitably involves all partners, including researchers and community members, in all phases of the research process, from study design to dissemination.	community capacity; participatory health research; community-based participatory action research
Community-Engaged Research (CEnR)	Represents a broad array of research approaches that emphasize academic-community partnerships focused on issues that affect the well-being of the community of focus.	community engagement in research
Community-Led Research	Any research process that seeks to not only balance power dynamics between researchers and communities, but to invert them as much as possible so that communities are in the lead from the outset, and researchers serve rather than extract from communities. ⁵³	Indigenous research methods; collective research methods
Community Science	Research that is focused on building strong communities through partnered prevention, treatment, education, and health promotion efforts. Often used within community psychology.	
Educational Action Research	Represents a broad range of action research conducted in educational and school settings.	teacher action research
Emancipatory Research	Research that shifts power and control from researchers to those who would be the research subjects. Often used in the context of disability research.	emancipatory action research
Health Impact Assessment (HIA)	A structured method to understand health consequences of projects and policies that takes into account those who might be impacted by a proposed policy.	community health needs assessment
Indigenous Research Methodologies	Research methods that are underpinned by Indigenous ontologies and epistemologies that involve direct engagement with Indigenous peoples and recognition of Country as a source of knowledge. They may question the assumptions of power, culture and embedded systemic racism in the research process, in research relationships, and in perceptions of Indigenous ways of knowing, being and doing.	Indigenist; Indigenous Standpoint; decolonising methodologies; Two eye seeing; critical race theory

Framework/Approach	Definition	Types/Variations
	Approaches may challenge traditional Western methods that undermine lived experiences of marginalized groups.	
Lived Experience Research	Seeks to privilege the voices of people with direct or first-hand experience of a topic or issue of concern to research or policy. For example, lived experience of disability, illness, pain, domestic violence or homelessness.	lived experience-led
Participatory Action Research (PAR)	Combines participation and action to understand and address societal issues. Emphasizes democratic processes in participation <i>with</i> others rather than research for research's sake conducted <i>on</i> people/communities.	participatory research; youth participatory action research
Participatory Evaluation	An approach that shares decision-making with stakeholders in the evaluation of a program or service in some point of the process.	empowerment evaluation; participatory or democratic evaluation
Participatory Health Research (PHR)	A research paradigm that most centrally values participation from stakeholders in the research process in specific ways to improve the quality and relevance of the research.	community-based participatory research
Participatory Rural Appraisal	An approach to community development in which rural people share decision-making in the programs and policies that affect them. Often used by non-governmental organizations.	rapid rural appraisal
Patient-Centred Outcomes Research	Research investigating the outcomes that are important to patients, with the rationale that clinical research is higher quality when it is informed by perspectives of the end users. Often used in healthcare research.	patient-centred research
Popular Education	A people-oriented, people-guided approach to education pioneered by Paulo Freire that centres people's life experiences and sees all participants as both teacher and learner.	popular adult education; critical education
Popular Epidemiology	A research process in which lay people gather data and work with experts to understand the epidemiology of disease and develop treatments.	environmental justice research
Practitioner Inquiry	A reflective approach to professional development for practitioners that involves asking research questions, collecting data, evaluating inquiries, and taking action.	practitioner action research, critical practitioner inquiry; teacher action research
Pragmatic Action Research	A cyclical progression of action research and collaborative evaluation designed to enhance co-generative learning among the participants with the end goal of solving problems.	co-generative research

Framework/Approach	Definition	Types/Variations
Relational method	A community-led research method guided by the principles and practices of relationality, power analysis and uncertainty, adapted from Saul Alinsky's community organising method and the pedagogy taught by the Industrial Areas Foundation that operates in 99 cities across the world.	community organising
Team Science	Collaborative, cross-disciplinary approaches to complex social problems that have many causes (e.g., climate change, chronic disease).	interdisciplinary team science
User-Centred Design Research	An iterative design process that involves users in the design of products or services that are intended for them.	design thinking; PostDesign; participatory design research; human-centred design

Endnotes

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- ¹ Nature, "Power to the People," *Nature* 562, no. 7 (2018): 7.
- ² By "researchers" we are referring primarily to academic researchers, while also referring to lived experience researcher-participants, acknowledging that in co-design the boundaries between the two are blurred.
- ³ See Nature, "Lived Experience: Shifting Focus," *Nature Mental Health* 1, no. 3 (2023): 145; and Christina Zorbas et al., "Community Lived Experience Should Be Central to Food Systems Policy," *Nature Food* 4, no. 1 (2023): 7-9.
- ⁴ OECD, *Innovative Citizen Participation and New Democratic Institutions* (June 2020).
- ⁵ Family Safety Victoria, "Family Violence Lived Experience Strategy: More Than Our Story: Action, Wisdom and Change," last modified April 12, 2022, <https://www.vic.gov.au/family-violence-lived-experience-strategy>.
- ⁶ Aboriginal Health & Medical Research Council Sydney, *NSW Aboriginal Health Ethics Guidelines: Key Principles* (2023), https://www.ahmrc.org.au/wp-content/uploads/2021/02/AHMRC_Health-Ethics-guidelines-2023_01.pdf.
- ⁷ See, for example, "Human Rights Based Approaches," Australian Human Rights Commission, accessed September 20, 2023, <https://humanrights.gov.au/our-work/rights-and-freedoms/human-rights-based-approaches>.
- ⁸ United Nations, *Convention on the Rights of Persons with Disabilities* (2006).
- ⁹ United Nations, *Declaration on the Rights of Indigenous Peoples* (2007).
- ¹⁰ Terri Janke, *True Tracks: Respecting Indigenous Knowledge and Culture* (Sydney: UNSW Press, 2021).
- ¹¹ Emma Blomkamp, "The Promise of Co-Design for Public Policy," *Australian Journal of Public Administration* 77, no. 4 (2018): 729-74.
- ¹² Brett Bellingham et al., *Co-Design Kickstarter* (Sydney: Community Mental Health Drug and Alcohol Research Network, 2023), <https://cmhdaresearchnetwork.com.au/resource/co-design-kickstarter/>: 6. Summarised with permission.
- ¹³ Bellingham, *Co-Design Kickstarter*, 5.
- ¹⁴ Katharine Sanderson, "High-Profile Autism Genetics Project Paused Amid Backlash," *Nature* 598 (2021): 17-18.
- ¹⁵ Jennifer R Banas et al., "Recruiting and Retaining People with Disabilities for Qualitative Health Research: Challenges and Solutions," *Qualitative Health Research* 29 (2019): 1056-64.
- ¹⁶ Damian Mellifont et al., "The Ableism Elephant in the Academy: A Study Examining Academia as Informed by Australian Scholars with Lived Experience," *Disability & Society* 34, no. 7-8 (2019): 1180-99.
- ¹⁷ Max Liboiron et al., "Equity in Author Order: A Feminist Laboratory's Approach," *Catalyst: Feminism, Theory, Technoscience* 3, no. 2 (2017): 1-17.
- ¹⁸ Zorbas, "Community Lived Experience," 7.
- ¹⁹ Louise Byrne et al., "Recovery as a Lived Experience Discipline: A Grounded Theory Study," *Issues in Mental Health Nursing* 36, no. 12 (2015): 935-43.
- ²⁰ For example, Kelly Ann McKercher, *Beyond Sticky Notes: Doing Co-Design for Real* (Sydney: Beyond Sticky Notes, 2020).
- ²¹ Quotations of co-authors are attributed throughout by initials in parentheses.
- ²² Ian McIntosh and Sharon Wright, "Exploring What the Notion of 'Lived Experience' Offers for Social Policy Analysis," *Journal of Social Policy* 48, no. 3 (2019): 449-67.
- ²³ Lisa M. Vaughn and Farrah Jacquez, "Participatory Research Methods – Choice Points in the Research Process," *Journal of Participatory Research Methods* 1, no. 1 (2020): 1.
- ²⁴ Linda Tuhiwai Smith, *Decolonizing Methodologies: Research and Indigenous Peoples* (London: Zed Books, 2021): 239.
- ²⁵ Vaughn and Jacquez, "Participatory Research Methods," 1.
- ²⁶ Paulo Freire, *Pedagogy of the Oppressed*, trans. Mayra Bergman Ramos (New York: Continuum, 2005): 17.
- ²⁷ Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford: Oxford University Press, 2007): 1.
- ²⁸ Sandra Moll et al., "Are You Really Doing 'Codesign'? Critical Reflections When Working with Vulnerable Populations," *BMJ Open* 10, no. 11 (2020).
- ²⁹ Critical theory includes feminism and critical ecology that dates back to the Frankfurt School in 1920s Germany, which built on Karl Marx's critique of capitalism. See Carolyn Merchant, ed., *Ecology* (New Jersey: Humanities Press, 1994).
- ³⁰ Freire, *Pedagogy*, 35. See translator's footnote.
- ³¹ *Ibid*, 48.
- ³² For example, for many years the practice development movement in healthcare (which has now evolved into quality improvement) represented a move to normalise participatory research principles and concepts into everyday practices of

practitioners. Over a period of 20 years or more, these methods have become embedded into continuous development of practice in healthcare settings around the world and have enabled practitioners without 'obvious' power to create meaningful change for themselves and others. See Brendan McCormack et al., eds., *Practice Development in Nursing*, 2nd ed. (Oxford: Wiley-Blackwell Publishing, 2013).

³³ Tineke Abma et al., *Participatory Research for Health and Social Well-Being* (Switzerland: Springer, 2019): 127.

³⁴ Brendan McCormack and Tanya McCance, *Person-Centred Practice in Nursing and Health Care: Theory and Practice* (Neward: John Wiley & Sons, 2016).

³⁵ Moll, "Are You Really Doing 'Codesign'?", 1.

³⁶ Amanda Tattersall and Marc Stears, "Building Knowledge through Powerful Relationships – Introducing the Relational Method," last updated June 18, 2021, <https://amandatatts.medium.com/building-knowledge-through-powerful-relationships-introducing-the-relational-method-327573cfb9ad>

³⁷ Sherry R. Arnstein, "A Ladder of Citizen Participation," *Journal of the American Institute of Planners* 35, no. 4 (1969): 216-24.

³⁸ Janke, *True Tracks*.

³⁹ Arnstein, "A Ladder of Citizen Participation"; International Association for Public Participation, "Spectrum of Public Participation" (2018), https://iap2.org.au/wp-content/uploads/2020/01/2018_IAP2_Spectrum.pdf; and, Vaughn and Jacquez, "Participatory Research Methods," 6 (adapted with permission). Arnstein's seminal model for democratic public participation conceptualises a ladder from non-participation at the bottom, through tokenistic involvement such as informing and consultation, to partnership and citizen control at the top of the ladder. The International Association for Public Participation's levels of participation articulates increasing impact on decision from inform to consult, involve, collaborate and empower. We have replaced some words of these models, reversed orders and added some in the centre, in an effort to capture the consensus across our perspectives explored in this report.

⁴⁰ Here scale isn't a reference to the "spread" of an idea, but the ability for an idea to catch fire in a different context. The strategic nature of place and experience play a role. This idea is elaborated in Amanda Tattersall, "Scale Is the Most Confusing Word in Social Change," last updated October 18, 2022, <https://amandatatts.medium.com/scale-is-the-most-confusing-word-in-social-change-9f5c65ab72d7/>.

⁴¹ Jijian Voronka, "The Politics of 'People with Lived Experience': Experiential Authority and the Risks of Strategic Essentialism," *Philosophy, Psychiatry, & Psychology* 23, no. 3 (2016): 189-201.

⁴² Brian Fay, *Critical Social Science : Liberation and Its Limits* (Ithaca: Cornell University Press, 1987).

⁴³ Amanda Tattersall, *Power in Coalition* (Ithaca: Cornell University Press, 2010).

⁴⁴ Brett Smith et al., "Co-Production: A Resource to Guide Co-Producing Research in the Sport, Exercise, and Health Sciences," *Qualitative Research in Sport Exercise Health* 15, no. 2 (2023): 159-87.

⁴⁵ This suggestion came from a Co-design Community of Practice meeting.

⁴⁶ Damian Mellifont et al., "The Ableism Elephant in the Academy: A Study Examining Academia as Informed by Australian Scholars with Lived Experience," *Disability & Society* 34, no. 7-8 (2019).

⁴⁷ John Allen et al., *Consumer Involvement with State Mental Health Authorities* (Alexandria, VA: National Association of Consumer/Survivor Mental Health Administrators and the National Association of State Mental Health Program Directors Medical Directors Council, 2010).

⁴⁸ Lynette Riley, "Community-Led Research through an Aboriginal Lens," in Victoria Rawlings, James Flexner, and Lynette Riley, eds., *Community-Led Research: Walking Many Pathways Together* (Sydney: Sydney University Press, 2021).

⁴⁹ Academics with "lived experience" in their title need to include and be led by people with lived experience of disability. See "Open letter from the Lived Experience workforce in response to the new Academy of LIVED-Experience," last updated April 7, 2021, <https://lewopenletter.wordpress.com>.

⁵⁰ National Institute for Health and Care Research, "PPI (Patient and Public Involvement) resources for applicants to NIHR research programmes," last updated December 18, 2019, <https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437>.

⁵¹ W. Sydney Callaghan, *Good Grief* (Newtownards, Northern Ireland: Colourpoint Books, 1999).

⁵² Vaughn and Jacquez, "Participatory Research Methods," 3-4.

⁵³ This paradigm is articulated in Sheelagh Daniels-Mayes, "Researcher or Student? Knowing When Not to Know in Community-Led Indigenous Research," in Victoria Rawlings, James Flexner, and Lynette Riley, eds., *Community-Led Research: Walking Many Pathways Together* (Sydney: Sydney University Press, 2021).

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