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Lived experience participation and influence in homelessness and housing policy, service design and practice

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Acronyms and abbreviations used in this report

ABS	Australian Bureau of Statistics
AHURI	Australian Housing and Urban Research Institute Limited
IAP2	International Association for Public Participation
LELAN	Lived Experience Leadership and Advocacy Network
LELs	Lived Experience Leaders
PESP	Peer Education and Support Program
PWLE	People or person with lived experience of housing precarity and homelessness
Seeds	Seeds of Affinity: Pathways for Women
VSAC	Victim Survivors' Advisory Council

Glossary

A list of definitions for terms commonly used by AHURI is available on the AHURI website ahuri.edu.au/glossary.

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Executive summary

Key points

- Over the last two decades, there has been an increasing expectation that people with lived experience (PWLE) participate in and influence community services. The reported benefits including accountability, improved effectiveness of policy and service delivery responses, and social change.
- The housing and homelessness policy landscape demonstrates an interest in including the voices of PWLE —yet few practical strategies to expand participation and influence are evident.
- This study examined the evidence for, and experiences of, lived experience participation and influence in housing and homelessness policy, service design and practice.
- While the literature consistently endorses the principle of lived experience participation, very few examples of influence, impact and outcomes of participation were found. Beyond the positive endorsement of lived-experience inclusion, we examined how it was applied in the literature, and categorised it according to the nature, extent, and level of agency and autonomy for PWLE.
- Focus groups with 47 PWLE in South Australia and Victoria found that meaningful participation and influence is far from what they experienced. Themes identified included PWLE feeling unseen, unheard and disempowered; experiences of structural violence; the wide scope for, and potential impact of, lived experience participation and influence; and immense opportunity for a lived experience workforce that is broader than peer work.
- Participants recommended and endorsed a series of principles, conditions and strategies that have the potential to advance meaningful lived experience participation and influence in the Australian housing and homelessness sectors.

It is well established that homelessness and housing precarity are entrenched social problems, and numerous policies and initiatives have attempted to address these issues. Over the last two decades, there has been an increasing expectation that PWLE participate in and influence community, social and health policy and practice. National and state homelessness policy and service delivery frameworks indicate an interest in including the voices of PWLE, yet few practical strategies to expand participation and influence have been developed.

The insights derived from lived experience and expertise can bring numerous benefits to organisations. For example, enhancing service legitimacy and accountability, improving effectiveness, developing new services, advocating for social change and enabling community cohesion (Doherty, McGuire et al. 2021; Martin, Ridley et al. 2017; Sandhu 2017). However, there are numerous barriers and challenges to lived experience participation, one of which Sandhu identifies thus: *'sharing power with experts by experience is rare, whilst excluding them from decision-making processes is common'* (Sandhu 2017: 7). This highlights that power relations and notions of expertise are central to lived experience participation.

Lived experience is defined in this project as the direct experience of homelessness, housing precarity and related factors such as family and domestic violence, mental distress, problematic substance-use patterns, incarceration, abuse throughout the life course, racism, poverty and discrimination. In contrast, lived expertise refers to the ways in which an individual's lived experiences are purposefully and intentionally applied to build and share knowledge and wisdom for the purposes of systems change and transformation.

Key findings

The findings span two areas:

1. Evidence from the peer-reviewed and grey literature on lived experience participation and influence in housing and homelessness policy and practice
2. Perspectives of PWLE on participation and influence in housing and homelessness policy and practice.

Our scoping review of 25 literature sources (16 grey and nine peer-reviewed), identified four themes:

1. Lived experience inclusion.
2. Lived experience participation.
3. The conditions and challenges to lived experience participation and influence.
4. The impacts of lived experience participation.

The literature consistently endorsed the principle of lived experience participation. However, very few examples of influence, impact and outcomes were found. Beyond the positive endorsement of lived experience inclusion, we examined how it was applied, the intentions for including PWLE, and the anticipated benefits.

Our analysis revealed aspects related to the nature, extent, and level of agency and autonomy available to PWLE in participation activities. We further identified that the levels of agency and autonomy can be categorised as low, medium and high. Finally, we compared the examples against the IAP2 Spectrum of Participation (International Association for Public Participation [IAP2] 2018).

Nine sources (four peer-reviewed and five grey literature) exemplified low-level participation, agency and autonomy. These sources were characterised by ad hoc consultative or advisory opportunities and PWLE having limited agency or autonomy. In contrast, seven sources (one peer-reviewed and six grey literature) demonstrated medium-level agency, autonomy and participation through the membership of PWLE on committees, advisory boards and co-design projects; PWLE regularly providing feedback and some opportunities for the agency, autonomy, authority and influence of PWLE. Finally, nine sources represented high-level participation (four peer-reviewed and five grey literature). These sources provided examples of PWLE leading or being involved in leadership teams; extensive, ongoing and frequent participation by PWLE; lived experience roles considered equal to non-lived-experience roles, and PWLE exercising agency and autonomy in many ways—including choosing their job or role title.

Analysis of the six focus groups with PWLE uncovered four major themes:

- Unseen, unheard and disempowered
- Structural violence
- The impact and scope of lived experience
- The lived experience workforce.

Unseen, unheard and disempowered

Focus-group participants emphasised and recounted enduring experiences of being unseen, unheard and disempowered. They argued that their marginalisation by services and practitioners was the result of assumptions and stereotypes about people who experience homelessness or who are social or public housing tenants. Participants pointed out that such experiences are disempowering and silencing. Consequently, when asked about lived experience participation and influence, participants thought it aspirational and far removed from their everyday lives.

Structural violence

Underpinning experiences of being unseen, unheard and disempowered were reports of unsafe, transactional and confronting encounters with services, systems and practitioners. Such experiences left participants feeling blamed, stigmatised, judged and disrespected. We conceptualise this as structural violence (Whittle, Palar et al. 2015). Despite participants recounting numerous examples of services and policies creating harm and emotional distress, they also expressed empathy and understanding regarding the pressure that services and practitioners face with increasing demand, limited resource availability and the gaps created by policy siloes.

The impact and scope of lived experience

Participants asserted the scope and far-reaching value of lived experience participation and influence. Participants argued that lived experience participation and influence improves policy, service design and practice, and undermines disempowerment and structural violence. It was suggested that collaborative practice involving PWLE in equal partnership with policy makers, service designers, providers and practitioners would maximise the contributions of all parties and lead to meaningful and practical ideas, strategies and solutions. Participants emphasised the need to be able to participate and influence through co-design, co-production and collaboration, arguing that co-designed responses and solutions would accurately reflect the needs and perspectives of those with lived experience.

The lived experience workforce

Focus-group participants emphasised the need for the development and expansion of the homelessness and housing lived experience workforce. Three elements underpin this theme: the range of roles, diversity, and working conditions. Participants argued that there were many roles that PWLE could fulfil. Key to these roles were equal pay and conditions, and recognition that their expertise was of equal value to that of practitioners who do not have lived experience. The role of systems navigator was seen as key to orienting service users, providing support, role-modelling recovery and healing, and explaining the policies and procedures of a service.

Policy development options

Roundtable discussions in South Australia and Victoria involved PWLE, policy makers, practitioners and academics. The participants emphasised the need to take pragmatic steps to move from aspirational consumer participation frameworks—a first step signifying intent—to practical action where PWLE have genuine influence and authority.

All roundtable participants argued for a rebalancing of current power relations, to place lived experience at the centre of all policy, practice and service design—including decision-making. Participants argued that minor changes to housing and homelessness policy and systems would only contribute to iterative, short-term and small-scale change. Participants provided feedback on and endorsed the following recommendations reflecting the principles, conditions and strategies for policy and practice development.

Principles

The principles include:

1. People with lived experience are recognised as having the capacity and the right to act and decide independently.
2. Lived experience is recognised, developed and promoted as a discipline, with equally valid claims to qualification, expertise and specialist knowledge.
3. Peer support between people with lived experience is valued and supported.
4. People with lived experience and expertise identify and lead research agendas.
5. Lived experience and expertise perspectives are systematically embedded in housing and homelessness policy, service design and practice.
6. Structural violence is acknowledged, and actions taken to promote structural justice.

Conditions

The conditions that enable lived experience influence and participation include:

1. People with lived experience are inducted and trained for lived experience and expertise roles. The training is ongoing, designed and delivered by PWLE and is trauma-informed.
2. Communities of practice are established by and for PWLE to share experiences, ideas and support. This may include formal and informal opportunities for debriefing and 'decompression'.
3. People with lived experience are always remunerated for their contributions. This remuneration should reflect parity with rates within the organisation—in other words, parity between lived and non-lived-experience staff—and payment benchmarks in other sectors where lived experience workforces are more developed.
4. Transparency, accountability and open communication are key conditions between PWLE and non-lived-experience stakeholders. This includes clarity about roles, tasks and activities, the intended length of the role, remuneration and other conditions.
5. A minimum of two PWLE work together on any task or in any setting.
6. Opportunities for PWLE to develop expertise, leadership abilities and other capabilities are abundant.
7. In addition to a peer-led community of practice, lived-experience-specific supervision (by and for PWLE) is available.
8. Relationships between people with and without lived experience (service providers, policy and other stakeholders) are central and based on mutual respect, reciprocity and active attention to power differentials.

Practical strategies

Finally, the practical strategies and policy development options that can advance the participation and influence of PWLE in housing and homelessness policy, service design and practice include:

1. Develop, implement and monitor transparent policy and practice mechanisms that account for the ways in which lived experience feedback is utilised and incorporated in policy, service design and practice settings.
2. Invest in the development of the lived experience workforce.
3. Co-design Lived Experience Standards.
4. Establish Lived Experience Panels.
5. Fund the development and operations of a Lived Experience Union.
6. Create and fund Lived Experience Commissioner roles.

The findings highlight that lived experience participation and influence in housing and homelessness is emerging, which suggests that there is potential for Australia to create world-leading approaches. However, this innovation will not be possible without investment, which includes ensuring that PWLE are paid for all participation activities. Responsibility for this reform cannot rest solely with homelessness and housing organisations, and must be supported in policy and funding arrangements. Tinkering with the homelessness and housing systems by simply incorporating low-level opportunities for lived experience participation and influence will not create the cultural and paradigmatic change this study has identified is required.

The study

With minimal Australian evidence on the level of participation and influence of PWLE in housing and homelessness policy and practice, and reflective of the team's commitments to value and centre lived experience and expertise, the study focussed solely on the perspectives of PWLE. We recognise the limitations to the study by not including policy and service provider stakeholders beyond the roundtable discussions.

The project team was a partnership between the Council to Homeless Persons, Victoria; Ngwala Willumbong, Victoria; Seeds of Affinity: Pathways for Women, South Australia; and academic researchers from RMIT University and the University of South Australia. The project employed six Lived Experience Leaders (LELs) who were paid at academic rates, supporting organisations were paid 17 per cent to administer payments to the LELs, and organisational representatives were reimbursed for their contributions to the project at academic pay rates. The LELs co-designed the focus-group interview guide, co-facilitated focus groups, analysed data, co-facilitated and presented at roundtable discussions, and contributed to authorship of this report.

The project addressed two research questions:

1. What is the evidence on the application and impacts of lived experience in housing and homelessness policy, practice and service design?
2. What principles, frameworks, models and strategies enable lived experience participation and influence in housing and homelessness policy, service design and practice?

1. Introduction

- **Successive state and federal government policies have sought to address the entrenched social problem of homelessness and housing precarity, with varying success.**
- **In the last two decades, the expectation of lived experience participation and influence has increased in health and human services.**
- **The homelessness and housing sectors lack the structures, systems, policies and practices for lived experience participation and influence that exist in other sectors.**
- **Within housing and homelessness sectors in Australia, lived experience participation is most evident in consumer participation frameworks, consumer advisory groups and ad hoc involvement in consultations, service delivery feedback mechanisms, education and research.**

1.1 Policy context

This section sets out the relevant policy contexts, highlights central issues and explores the research focus—including the positionality of the research team in relation to lived experience.

It is well established that homelessness and housing precarity are entrenched social problems. On the night of the 2021 Australian Census, 122,494 people were estimated to be homeless (Australian Bureau of Statistics [ABS] 2023). This represents an increase of 5.2 per cent since 2016, with females accounting for 82 per cent of the increase (ABS 2023). According to the same data, 56 per cent of homeless people were male, 21 per cent were aged 25–34 years, and 20 per cent were First Nations peoples (ABS 2023). The Northern Territory recorded the highest rate of homelessness, and Western Australia the lowest. Of those experiencing homelessness, two in five (39.1%) were living in severely crowded dwellings; one in five (19.8%) were in supported homelessness accommodation, and one in six (18.1%) were living in boarding houses.

Reflecting on the locations in which this study took place, South Australia experienced a 19.3 per cent increase and Victoria a 24 per cent increase in homelessness since 2016 (ABS 2023). Victoria continues a trend of having the lowest proportion of social housing nationally. Public and community housing residents comprise 2.8 per cent of households, compared to the national average of 4.1 per cent and the South Australian average of 6 per cent (ABS 2023).

A range of policies and strategies to address homelessness and improve housing stability has been introduced over many years and with varying impact. The federal government is currently developing a National Housing and Homelessness Plan ('the Plan'), with stated commitments to social housing and Housing First approaches. We note that this work addresses a 15-year gap since the last national homelessness plan and 30 years since a national housing plan (Callister 2023).

The approach taken to develop the Plan has relevance for this research, as it sought a wide range of stakeholder inputs through community forums, webinars, stakeholder roundtables and targeted discussions (Commonwealth of Australia 2024: 13). Over 1700 people participated in the consultation process, with 24 per cent identifying as community members. Some 517 submissions were received. The development of the Plan highlights a national commitment to '*engaging people who have experienced homelessness in designing programs and services*' (Mares 2024). Further, the related Issues Paper states that: '*The Plan will also draw on insights from the public, including those with lived experience of housing stress or homelessness*' (Commonwealth of Australia 2023: 7).

While the Summary Report on Consultations for the Plan does not reference co-design with PWLE, it expresses a principle of '*making sure we include those who have faced homelessness or struggled to find secure housing when designing programs and services*' (Commonwealth of Australia 2024: 4) and ensuring '*each person's unique story and needs*' are considered alongside '*understanding the impact of trauma*' (2024: 2). This suggests a commitment to including consumer voices within the federal housing and homelessness policy arena. In relation to Housing First, we note that the involvement of PWLE is central to the approach (Padgett, Henwood et al. 2016).

1.1.1 Victorian policy context

Numerous Victorian policies focus on consumer participation and co-design. In October 2019, the then Department of Health and Human Services (now known as the Department of Families, Fairness and Housing) released *Client voice framework for community services*. The framework is not specific to homelessness and housing, but it is applicable, as it promotes the need for all levels of service delivery to '*critically assess their current practice in relation to seeking, hearing and responding to the client voice*' (Department of Health and Human Services 2019). The framework is based on five principles:

1. The client voice is essential for quality and safety.
2. Clients have expertise.
3. The client voice is part of everyone's role.
4. There are many client voices.
5. The client voice leads to action (Department of Health and Human Services 2019: 10).

More recently, the Department of Families, Fairness and Housing's Strategic Plan 2022–26 identifies in Outcome Five that it aims to '*increase the voice of clients, people with lived experience and diverse communities in the design, delivery and evaluation of policies and services*' (Department of Families, Fairness and Housing 2024).

A 2020 audit of Victoria's Homelessness and Rough Sleeping Action Plan (HRSAP) involved consultation with PWLE, including members of the Council to Homeless Person's Peer Education and Support Program (PESP). The audit recommended creating and strengthening feedback from service users and the establishment of lived experience advisory groups (Victorian Auditor General's Office 2020). These recommendations were picked up in the Victorian Government's Homelessness Program Guidelines (2021: 6), noting that *'governance arrangements will ensure ... consumer participation: increasing awareness and understanding of the consumer perspective, and designing systems and processes to enhance their participation'*.

The Victorian 2020 Inquiry into Homelessness emphasised lived experience submissions and presentations. It stated in its final report that *'the Committee has kept front of mind the profound individual traumas and the human impact of homelessness throughout'* (Parliament of Victoria 2021: 30). However, although the Inquiry recognised the significant impact of homelessness, it did not produce recommendations related to the participation and influence of PWLE in the co-design of policies, services or practice standards.

The Victorian Victim Survivors' Advisory Council (VSAC) is a lived experience initiative stemming from the 2016 Victorian Royal Commission into Family Violence. VSAC aims to influence policy, legislative and practice reform, central to which is lived experience:

There is a clear and growing movement to support the inclusion of lived experience in the design, implementation and evaluation of family violence services and for communities to participate in decision making on the issues that affect their lives. (VSAC 2023: 6)

The VSAC lived experience strategy addresses language, the history of the Council, working relationships between victim-survivors and other stakeholders and phases for enacting the strategy (VSAC 2023). While the group's focus is family violence, the links between family violence and homelessness and housing precarity mean that it has relevance for this project.

For over 10 years, various homelessness services networks in Victoria have stated their intention to facilitate and promote client or consumer participation. This has resulted in most area networks developing a consumer participation strategy, and many implementing a client survey every few years. The activities of seven groups and organisations, involving 165 documents, have been assessed by Constantine, who identified that these consumer participation strategies *'appear to be largely independent projects designed to display possibilities and promote consumer participation, regardless of regulatory and funding requirements'* (2023: 4). This suggests a longstanding focus on participation by many homelessness services and networks in Victoria. Constantine's analysis highlighted three key conceptual themes and dichotomies of *'experience or expertise; lived or living experience; feedback or influence'* (2023: 8–10).

The other relevant policy context in Victoria is the announcement that 44 high-rise towers in Victoria will be demolished and redeveloped to include a mix of housing types (Department of Premier and Cabinet 2023). This redevelopment is likely to put significant pressure on the already low and insufficient social housing stock (Council to Homeless Persons 2024). One of the focus groups for this project involved participants living in a block of apartments that will be redeveloped, and the participants' contributions were informed by their sense of uncertainty and housing insecurity.

1.1.2 South Australian policy context

In South Australia, *Our Housing Future Strategy 2020–2030* details a 10-year plan for better housing outcomes. Ninety-three PWLE were consulted during development of the plan (The Australian Centre for Social Innovation 2019). The Strategy seeks to address service fragmentation and enhance collaboration through the funding of five regional homelessness alliances and one statewide domestic and family violence alliance. The Strategy makes several mentions of the involvement of PWLE, including ‘*respecting lived experience*’ through the incorporation of ‘*the voice and perspectives of people with lived experience into all policy, practice and service decision making*’ (South Australian Housing Authority 2021: 6), along with ‘*the creation of transparency and accountability through the incorporation of lived experience voices*’ (2021: 6) and ‘*embedding lived experience in service planning and delivery*’ (2021: 10). At the time of concluding this project, the Strategy had not reported evaluation data on the lived experience aims.

Other lived experience activities in South Australia include the co-design workshops delivered by Shelter SA and the South Australian Housing Authority for the Housing Security for Older Women Taskforce and involving lived experience advocates and culminated in a publication focussing on improving housing security for older women (Government of South Australia 2023). The South Australian Lived Experience Leadership and Advocacy Network (LELAN) is a consumer-led independent peak body for people with lived experience of mental distress, social issues or injustice in South Australia (LELAN n.d.). Although LELAN does not specifically address experiences of homelessness and housing precarity, their work has relevance for the participation and influence of PWLE.

1.2 Existing research

The insights derived from lived experience and expertise can bring numerous benefits to organisations, including enhancing service legitimacy and accountability, improving effectiveness, developing new services, advocating for social change, and community cohesion (Doherty, McGuire et al. 2021; Martin, Ridley et al. 2017; Sandhu 2017).

However, there are limits to operationalising the meaningful participation, influence and leadership of PWLE, as Sandhu notes: ‘*sharing power with experts by experience is rare, whilst excluding them from decision-making processes is common*’ (Sandhu 2017: 7). Numerous barriers are cited in the broader lived experience literature, including:

- professionals gatekeeping rather than enabling PWLE to participate
- tokenism
- limited or no reciprocity
- no reimbursement of PWLE for their expert contributions
- not recognising PWLE’s authority, autonomy, power and privilege and experiences of stigma (Sandhu 2017).

The literature on homelessness, housing and lived experience positions lived experience as central to the enhancement of service provision, policy development and practice. Studies often focus on experiences of service interventions, rather than considering the participation of PWLE in co-designing research, policy, service design and services provided (see Stonehouse, Threlkeld et al. 2021). Discussion on engaging PWLE—who are often referred to as ‘consumers’ in the literature—as consultants and contributors in areas such as service delivery policies, advisory groups, peer work, evaluations and research is growing (O’Donovan, Russell et al. 2019; Stonehouse, Theobald et al. 2022). Despite the generally positive positioning of lived experience in the housing and homelessness-related literature, few practical strategies to expand participation and influence are shared. In other words, a commitment to or interest in lived experience participation does not automatically result in participatory and co-design approaches that position PWLE as having equal expertise.


Considerations of lived experience rest on understanding the form and nature of participation. Two sources inform our work. Sherry Arnstein's work in the 1960s (republished in 2019) on citizen participation in impoverished communities in Chicago is highly influential and has led to the development of many other frameworks for participation (Arnstein 2019). The International Association for Public Participation (IAP2) has adapted and conceptualised Arnstein's seminal work in the IAP2 Spectrum of Public Participation (2018), reproduced with permission in Figure 1.

Figure 1: Spectrum of public participation

IAP2 Spectrum of Public Participation



IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION 					
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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The Spectrum highlights varying levels of participation and could be extended further to include co-production and user-led initiatives that go beyond empowerment.

At the 'Inform' end of the Spectrum, we would expect that PWLE are provided with information—for example, service users are advised of a change in policy that expands or constricts access to a service. The 'Consult' sphere invites feedback, and a common example in homelessness or housing services would be the suggestion box (and digital equivalent), where service users are invited to share their views on the strengths and opportunities for improvement in a service or policy. When it comes to 'Involve', there is increased participation by PWLE, and an example is service users sharing their concerns about an issue, offering suggestions, and expecting to be informed about how their ideas shaped the decision or outcome. 'Collaborate' extends participation and introduces more influencing opportunities for PWLE, who could expect to see how their suggestions influence outcomes and decisions. Finally, the 'Empower' domain places decision-making authority with PWLE.

In suggesting the Spectrum could be extended to co-production and leadership by PWLE, we assert that PWLE would identify problems and issues, scope responses (including research designs), lead and implement strategies and change and ensure evaluation of their activities and work.

Aligned with the ideas presented on participation, co-design is often cited as an antidote to the exclusion of lived experience perspectives. However, like many popular approaches, co-design is at risk of co-option—particularly if the supposed co-design activities are more akin to the IAP2 spheres of involvement or consultation (IAP2 2018). Co-design requires time, resources, and a deep commitment to be guided by the process—which might not be where the project leaders hoped or expected to land. Such practices often treat participation as a formality, reducing it to a compliance exercise rather than meaningful engagement (Davies, Gray et al. 2014). Co-design requires more than once-off consultations or focus groups, which can be tokenistic—particularly if the views expressed by PWLE are not recognised or incorporated into decisions (Mullins, Kelly et al. 2021).

It is recognised that the participation and influence of PWLE can be difficult and challenging, as well as both resource-intensive and time-intensive. However, there are reports in the literature of lived experience participation improving confidence, building skills, increasing social connectedness and creating employment opportunities (Campbell, Campbell et al. 2021; Mullins, Kelly et al. 2021). Philips and Kuyini's (2018) Australian study on participation in homelessness services identified various obstacles including staff attitudes towards service users that were judgemental, authoritarian and dismissive. Additional challenges in conducting participatory research reported in the literature include funding, rigid timelines, ethics approvals, conflict between stakeholders, and limited experience of working with PWLE (Campbell, Campbell 2021; Nelson and Zamora-Kapoor 2016).

The Housing First approach centres the principle of listening to PWLE with service user choice and peer support central components (Padgett, Henwood et al. 2016). Longitudinal studies have found that Housing First approaches that centre service user choice have been successful in reducing hospitalisation and incarceration rates, and providing access to other service systems (Tsemberis, Gulcur et al. 2004). A co-designed Housing First project in Auckland, Aotearoa New Zealand, used a design process to adapt the Pathways to Housing First model for Aotearoa and the Auckland city centre. The design team included Māori people as well as those with lived experience of rough sleeping. The project team concluded that co-design requires an intentionally collaborative environment (Lifewise 2017).

Several of the LELs brought the experience of incarceration to the project. Based on the established relationship between Seeds and an academic member of the team, the team focussed solely on the experiences and views of formerly incarcerated women in South Australia.

Women in prison are the fastest-growing cohort of those incarcerated in Australia and across the globe (World Prison Brief 2018), with 30 per cent of women in prison in Australia identifying as Aboriginal, and over 60 per cent being a parent to a child under the age of 18. The Adelaide Women's Prison is the only prison for South Australian women and has the highest remand-in-custody rate of any prison in Australia (ABS 2023). When women do not have suitable bail addresses and are experiencing family and domestic violence, they remain in prison because there are no other suitable release options (Meyer 2021). Women tend to have shorter periods in custody than men, which commonly precludes them from formal post-release support—including housing (Anti-Discrimination Commission of Queensland 2019). When released, many women have no option but to return to abusive relationships, unsafe housing or directly into homelessness (Carlton and Segrave 2011). Regardless of the length of sentence, the impact of incarceration is significant, as women lose their housing, employment, possessions and children upon entering prison (Dowell, Mejia et al. 2018).

Given our project includes a scoping review on the evidence of participation and influence of PWLE as an element of this study, an in-depth and focussed exploration of the literature is presented in Chapter 2.

1.3 Research methods and methodology

1.3.1 Conceptualising lived experience and expertise

Lived experience can be defined and conceptualised in many ways, and it is not uncommon to hear the refrain 'but doesn't everyone have lived experience?'. To avoid relativism and promote specificity, we utilise Sandhu's (2019: 3) definition of lived experience: '*Direct, first-hand experience, past or present, of a social issue(s) and/or injustice(s)*', and lived expertise as the '*Knowledge, perspectives, insights, and understanding gathered through lived experience*.' This foregrounds how we conceptualise lived experience and expertise in this project—which are presented interchangeably at times—along with intersecting experiences of disadvantage and marginalisation that shape everyday lives (Crenshaw 1991). Therefore, when we refer to lived experience in this project, we mean the direct experience of homelessness, housing precarity and related factors such as family and domestic violence, mental distress, problematic substance-use patterns, incarceration, abuse throughout the life course, racism, poverty and discrimination. When we refer to lived expertise, we are drawing attention to how an individual's lived experiences have been purposefully and intentionally applied to build and share knowledge and wisdom, usually in efforts to promote change and deeper valuing of PWLE.

This conceptualisation extends to considering how lived experience and expertise are presented. For example, the participation of PWLE in the housing and homelessness area, while relatively new in comparison to other fields (Davies, Gray et al. 2014), is characterised by sources that **tell the story** of lived experiences of housing insecurity, homelessness and related issues—for example, Campbell, Campbell et al. 2021; O'Donovan, Russell et al. 2019; Stonehouse, Threlkeld et al. 2021. In other words, these sources represent the lived experiences of people by describing them and what they have experienced; often including quotes from PWLE. However, there is little scholarly research or grey literature that systematically explores instances of PWLE **participating and influencing policy**, service design and practice. This highlights an important point and draws attention to whether PWLE are leading, influencing, deciding and speaking for themselves, or others such as researchers, educators, policy makers and practitioners speak for or about PWLE.

1.3.2 Research focus

The meaningful involvement of PWLE contributes to health and human services policy, service design, education and research (Doherty, McGuire et al. 2021; Martin, Ridley et al. 2017) and promotes accountability and efficiency in policy and practice (Sandhu 2019). The mantra of '*nothing about us, without us*' (Charlton 1998: 14) captures both the history and intent of PWLE's aspirations to inform policy and services. The participation of PWLE takes many forms, as evidenced in the variety of terms used, such as 'lived experience', 'lived expertise', 'experts by experience' and 'consumer involvement'.

Given the growing and very reasonable requirement that PWLE are involved in decisions that impact their lives across policy, practice, service design, research and education domains—along with the limited and ad hoc responses of the housing and homelessness systems to this trend—the research scoped the nature of lived experience participation and influence in housing and homelessness. With little documented Australian evidence on the level of participation and influence of PWLE, and reflective of the team's commitments to value and centre lived experience and expertise, the study focussed solely on the perspectives of PWLE. We recognise that this produces limitations to the study, as:

- policy and service provider stakeholders are not represented
- the size of the project limited the diversity of PWLE who contributed.

Efforts made to address the the lack of PWLE diversity are detailed in Section 1.3.5.

This project operated from the principle of foregrounding the perspectives of PWLE of homelessness and housing precarity in conceptualisation, design, implementation and reporting. This reflects the team's commitment to value, centre and privilege lived experience perspectives and simultaneously counter epistemic injustice, which is *'a wrong done to someone specifically in their capacity as a knower'* (Fricker 2007: 1).

This overt stance draws attention to the epistemic marginalisation of individuals or groups based on their lived experience of homelessness, housing precarity and other intersecting factors.

The study was co-designed by representatives from the Council to Homeless Persons, Victoria; Ngwala Willumbong, Victoria; Seeds of Affinity: Pathways for Women, South Australia; and academic researchers from RMIT University and the University of South Australia.

Many of the members of the team have lived experience of homelessness, housing precarity and family and sexual violence. Co-design methods were used to respond to the research brief from AHURI. We do not claim an authentic co-production approach (Slay and Stephens 2013), which is characterised by those experiencing the issue(s) identifying the problem and leading the design of a response (in this case, a research project design). However, we have held co-design and collaborative research principles at the forefront of our work and created the conditions for the LELs to enact high-level participation, agency and autonomy in the project.

The project employed six LELs through Seeds (n=1), Ngwala Willumbong (n=3) and the Council to Homeless Persons (n=2). Organisational representatives and LELs from Seeds, Ngwala Willumbong and Council to Homeless Persons were reimbursed at academic pay rates and the supporting organisations were paid 17 per cent overhead costs to administer payments to the LELs. The LELs were invited to participate in all elements of the research, dependent on their interest, expertise and desire to develop research skills and knowledge. The LELs:

- co-designed the focus-group interview guide
- co-facilitated focus groups
- analysed data
- co-facilitated and presented at roundtable discussions
- contributed to authorship of this report.

The limited timeframe of the research project impinged on opportunities for organic relationships and trust-building to develop. Consequently, the team intentionally attended to making space inside and outside the regular team meetings to connect, get to know each other and create the conditions for authentic and inclusive lived experience approaches, such as ensuring language was accessible—that is, avoiding academic or industry jargon—and co-creating opportunities for the LELs to lead, contribute and share their critiques of academic practices.

1.3.3 Research methods

The project incorporated three main methods: a scoping review of peer-reviewed and grey literature, focus groups with PWLE, and roundtable discussions. The positionality of the research team (described in Section 1.2.3) in valuing lived experience mediated the project activities. For example, during participant recruitment, the lead investigator worked relationally, speaking by telephone or email (depending on the person's preference) to every potential participant, introducing herself, the project, the team and explaining the team's values and commitment to value and centre lived experience. Some of these conversations were an hour in duration but were invaluable in providing an opportunity for the potential participant to fully understand the project (including its limits—for example, not being able to address people's housing crises) and most importantly, provide informed consent. Participants reflected that they appreciated the opportunity to be seen, heard and recognised as an expert, even before they joined a focus group.

Similarly, focus groups opened with the facilitators (one LEL and one academic researcher or two academic researchers) sharing their positionality, experience and values in relation to lived experience; their commitment to avoid 'damage centred' (Tuck 2009: 409) homelessness and housing research, and their intention to listen deeply and learn from those with direct experience. Focus-group participants frequently commented on how they felt welcomed and valued for their expertise. This was further reflected in the number of focus-group participants who re-engaged by joining the roundtable discussions, suggesting they felt valued, heard and respected by the research team. Institutional ethics approval was gained from RMIT University (26244) and the University of South Australia (205713). The project was based on the questions and associated methods shown in Table 1, which were expanded and adapted from the original research design:

Table 1: Research questions and methods

Research questions	Methods
<ul style="list-style-type: none"> • Research Question 1: What is the evidence on the application and impacts of lived experience in housing and homelessness policy, practice and service design? Supported by sub-questions of: • What is the influence of lived experience participation in housing and homelessness policy, practice and service design? • What is the nature of lived experience participation and/or leadership in housing and homelessness policy, practice and service design? • What are the conditions for people with lived experience to participate, influence or lead in housing and homelessness policy, practice and service design? • What is the impact of lived experience participation in housing and homelessness policy, practice and service design? 	<ul style="list-style-type: none"> • Scoping review • Focus groups • Roundtables
<ul style="list-style-type: none"> • Research Question 2: What principles, frameworks, models and strategies enable lived experience participation and influence in housing and homelessness policy, service design and practice? 	<ul style="list-style-type: none"> • Focus groups • Roundtables

Source: Authors

1.3.4 Scoping review methods

The scoping review methodology of Arksey and O'Malley (2005) guided the investigation of Research Question 1, as did the framework developed by Godin, Stapleton et al. (2015) for sourcing and reviewing grey literature. Findings from the scoping review are detailed in Chapter 2.

To develop the search framework, the research team brainstormed terms and concepts relevant to the scoping review. This activity was informed by the team's lived, professional and academic knowledge of, and experience in, homelessness and housing precarity. The final search terms can be found in Appendix 1. This activity produced 35 keywords which, after initial searching, were refined to 15 terms. The inclusion criteria of peer-reviewed, published between 2003 and 2023 and English language framed the search strategies. Jessica Stubbings consulted an RMIT librarian who assisted in refining the key words and terms, and suggested relevant databases for the peer-reviewed literature. The databases included ProQuest, Informit, Taylor & Francis, Oxford Academy, and Scopus. While JSTOR was suggested by the librarian, it was ultimately excluded because of site inaccessibility. The searches were constrained in some databases because of the limit on the number (n=6) of searchable keywords.

While there are challenges in systematically searching grey literature, the LELs and other stakeholders interested in the project advised that most of the material on lived experience participation would be found outside the peer-reviewed literature. The framework and five steps developed by Godin, Stapleton et al. (2015) for the systematic review and searching of grey literature guided our work. Searches were conducted on the following databases: Greynet International, Trove, Worldcat, BASE, RMIT Research Repository. (Several other databases did not permit access or enable advanced searches.)

Customised Google searches were conducted with the search terms (which are listed in Appendix 1). Due to time constraints, we did not follow the recommendation by Godin, Stapleton et al. (2015) to comprehensively consult content experts to identify other sources. However, several research team members are experts in this area, and they identified and suggested relevant literature throughout the project. We also invited interested stakeholders to share key documents and links with us.

A total of 114 peer-reviewed papers were identified in the initial search, with 58 duplicates found and removed. The remaining 56 abstracts were independently screened by pairs of researchers using the Covidence platform. Of these 56 citations, 21 were selected for full-text review by two researchers. A further 12 sources were excluded as they did not meet the inclusion criteria, leaving nine papers that were reviewed in full. In the case of disagreement between reviewers, a third researcher arbitrated and decided if the source was included.

Based on the advice of the RMIT librarian, grey literature sources were categorised in three ways; general web-based information; organisational materials; and documents presented in PDF form. Initially, the team planned to review 100 sources from each of these categories (n=300). However, once the sources were exported into a spreadsheet for initial screening, it was clear that the volume of materials was beyond the capacity of the team and its associated resources—especially as the sources often linked to further sources.

Consequently, the research team reduced this to 50 sources from each customised search. This resulted in the screening of 150 online sources in total. Pairs of researchers were assigned to review each category (general, organisational and documentary). This resulted in the inclusion of 26 sources that were read in full by two researchers. A further 10 sources were excluded or merged when similar materials were reported in different formats—for example, an organisation might report the same material on a webpage and as a PDF document. The final number of grey literature sources included was 16. As with the peer-reviewed literature, disputes between pairs of researchers were arbitrated by a third member of the team.

The results from all included materials (n=25) were analysed using Braun and Clarke's (2006) approach to thematic analysis. Initial analysis was allocated to one research team member who undertook the following steps: familiarisation with the data, initial coding, generation of potential themes, and finalising themes. Preliminary codes and potential themes were generated collaboratively between two researchers, with final themes iteratively developed, negotiated and agreed upon across academic and grey literature.

1.3.5 Focus groups

Six focus groups were convened in Victoria (n=5) and South Australia (n=1). In Victoria, the team circulated information via email on the study to key stakeholders and through the lead investigator attending Victorian Statewide Homelessness Network meetings (two metropolitan and one regional) and meeting with coordinators of these networks. The project was explained, and agencies were asked to support the project by advertising the study to PWLE with current or past experiences of homelessness or housing precarity. The initial recruitment activities did not attract sufficient participants for the Victorian focus groups, so a second wave of recruitment, led by the LELs and the Council to Homeless Persons, culminated in 47 people being recruited. Inclusion criteria included having had an experience of homelessness or housing precarity, being aged over 18 years, and being located in either Victoria or South Australia.

Researchers attempted to recruit PWLE who were members of LGBTIQ+ communities but were unsuccessful, with service delivery partners saying that the demand for services and workforce challenges outweighed their ability to assist in recruiting research participants. Ngwala Willumbong, as a partner to the project, also sought to host an Aboriginal and Torres Strait Islander focus group, but was unable to organise this within the project timeframe because of the pressure of service demands.

Focus-group participant details are summarised in Table 2.

Table 2: Focus-group participant details

Location	Number of participants	Format	Characteristics of participants
North, south and east metropolitan areas of Victoria	33	In-person focus groups	People with lived experience of homelessness, housing precarity and insecure tenure
Adelaide, South Australia	7	In-person	Women with lived experience of homelessness, housing precarity and insecure tenure and incarceration
Victoria	7	Online	LELs and advocates

Source: Authors

The South Australian focus group built on the partnership with formerly incarcerated women through Seeds of Affinity: Pathways for Women and Dr Michele Jarldorn. Seeds is a grassroots community organisation run by and for currently and formerly incarcerated women in South Australia. The seven focus-group participants represented experiences and perspectives of a group for whom histories of violence, abuse, poverty, physical and mental health, and entanglement with the criminal justice system inform and create experiences of housing precarity and homelessness (Australian Institute of Health and Welfare 2022; Breuer, Remond et al. 2021; Jarldorn, Neill et al. 2022).

The focus groups were co-facilitated by a LEL and an academic researcher or two academic researchers, and utilised an interview guide (see Appendix 3) that was co-designed by the LELs to emphasise influence, not just participation. The focus groups were audio-recorded and professionally transcribed.

Data from the focus groups were analysed using Braun and Clarke's (2006) approach to thematic analysis. One LEL worked with other researchers in data analysis. To ensure a consistent approach, a framework based on Braun and Clark's (2006) approach was developed by the lead investigator and applied by the analytic team. The framework included definitions, templates for each of the analytic steps and examples. A focus-group transcript was allocated to two team members who did not facilitate that particular focus group. Each researcher worked independently and undertook the following steps: familiarisation with the transcript; coding, building initial themes and finalising the themes (Braun and Clark 2006). Paired researchers then met and discussed their themes and shared one to two sentence definitions for each theme.

Iterative agreement was reached between the pairs on the themes and their definitions, accompanied by quotes from PWLE. The entire analytic team (n=8) then met, and the pairs presented their themes with definitions and quotes. The team discussed, negotiated, and agreed upon themes common to all transcripts. These themes are reported in Chapter 3.

1.3.6 Roundtables

The roundtables provided an opportunity for interested focus-group participants, lived experience advocates, service providers, and policy makers to reflect on the emergent findings, and to collaboratively develop policy and practice recommendations for advancing lived experience participation and influence in the homelessness and housing sectors.

Nine Victorian focus-group participants expressed interest in contributing further to the research, and they were invited to the roundtable discussion along with another four lived experience advocates who had indicated their interest in the project (and who had lived experience of homelessness or housing precarity). Eleven of the 13 invited PWLE joined the face-to-face roundtable along with two peer workers and seven service provider, policy and academic stakeholders. The roundtable was facilitated by LEL and team member Morgan Cataldo, and lead investigator Robyn Martin. Opportunities for participants to meet and connect were created before the emergent findings from the scoping review and focus groups were presented. These findings were endorsed by participants. Following the presentation of findings, participants worked in small groups and developed recommendations for advancing lived experience participation and influence in the homelessness and housing sectors. These recommendations were then thematically analysed by the research team and returned to the participants for their feedback, which was incorporated (see Appendix 3).

In South Australia, the roundtable involved four formerly incarcerated women and nine service provider, policy maker and peak body representatives from housing, homelessness and domestic violence services. The shared conversations between these services and the formerly incarcerated women created synergies and enabled networking, involving many practitioners and managers who were currently implementing or were interested in incorporating lived experience advocacy in their services. As with the Melbourne roundtable, participants shared their ideas on practical steps and suggestions to advance lived experience participation and influence.

1.3.7 Trustworthiness of findings

The findings from the focus groups were endorsed by roundtable participants, stating that they resonated with lived and professional experience and knowledge. Further comments and ideas were shared by participants, including:

- gatekeeping in services
- the challenge for services in responding to intersectional identities
- experiences of oppression
- funding trends that inadvertently exclude some groups and individuals.

The participants also described:

- the lack of cultural safety within services
- the risks associated with insecure housing for women
- the need for deep recognition of how dangerous street-based homelessness is
- the lack of trauma awareness within services
- the need for a central and deep focus on recovery from experiences of homelessness.

Additionally, recommendations from the two roundtable discussions were collated and presented thematically to participants. This feedback was incorporated, and participants indicated they endorsed the recommendations. The final recommendations were shared with participants.

2. The evidence for lived experience participation and influence

- **There is limited evidence on the application and impacts of lived experience participation and influence in housing and homelessness.**
- **The IAP2 Spectrum of Participation provides a useful framework for understanding lived experience participation, as do assessment factors such as extent, nature and low, medium and high levels of autonomy and agency available to those with lived experience.**
- **The housing- and homelessness-related literature endorses and supports the inclusion of lived experience perspectives.**
- **There is limited evidence on the degree to which people with lived experience exert influence that leads to change and improvements in the housing and homelessness sector.**

The scoping review identified and examined the evidence on the application and impacts of lived experience in housing and homelessness policy, practice and service design.

Literature was sourced from the United Kingdom (n=12), the United States (n=6) Australia (n=5) and Canada (n=2). The small number (n=9) of academic sources reflects the emergent nature of lived experience participation and influence in housing and homelessness. The comparatively higher number of grey literature sources (n=16) suggests that recent activity to embed lived experience participation and influence is occurring outside academic and research spheres—which is fitting for an emergent field. This also reflects the advice from the LELs and other stakeholders and Sandhu's (2017: 27) argument that *'small elements of the social sector are leaps ahead compared to others in terms of their development and use of the concept'* of lived experience.

Our thematic analysis of the combined literature sources identified four main themes:

- Lived experience inclusion.
- Lived experience participation.
- The conditions and challenges to lived experience participation and influence.
- The impacts of lived experience participation.

The literature emphasised the importance of lived experience participation. However, while aspiration is evident, there are very few examples of influence, impact and outcomes. Conditions for participation and barriers and challenges are reported; yet how these factors relate to influence in policy, practice and service design is rarely reported. We explore these themes in more detail in the sections that follow.

2.1 Lived experience inclusion

The scoping review revealed that all sources expressed a commitment to some form of lived experience, with most reflecting the spheres of information, consultation and some involvement (International Association of Public Participation 2018). We sought to extend understanding beyond the endorsement of lived experience inclusion and examined how it was applied, the underlying intentions and the anticipated benefits.

We share two examples that are typical of many sources reviewed, claiming lived experience participation but, upon investigation, revealing more aspiration than action.

The 2009 study by Washington, Moxley et al. explored barriers for overcoming homelessness for older African Americans in a western region of the United States. Two academics established the project, which transitioned from action research to participatory action research methods in the fourth year. The authors state they adopted participatory research methods when they ‘embraced reflexivity and engagement with the homeless experience through in-depth encounters with participants and firsthand experience with homelessness’ (Washington, Moxley et al. 2009: 146). This suggests the researchers did not start out with an intention to elevate the participation of PWLE but instead adopted a more inclusive approach some years into the project, and after being emotionally affected by the older women’s experiences of homelessness. Embracing the older women’s perspectives is reported to have been the catalyst for improving the investigators’ knowledge and understanding, and led to the development of frameworks, tools and interventions (Washington, Moxley et al. 2009). In a sense, the researchers learnt and developed through and by the lived experience of the older women. The involvement of PWLE in this project in the fourth year highlighted the benefits for the investigators; however, it did not mention the purpose or drive to elevate PWLE or provide them with opportunities to participate or influence.

Another example of the aspiration and interest in lived experience without mobilising the participation of PWLE is the Canadian-based research on low-income older adults’ experiences of aging, homelessness and precariousness (Wyndham-West, Odger et al. 2022). The authors state that in sharing the participants’ lived experiences they sought to build awareness of PWLE and improve policy responses, yet the level of participation by PWLE appears minimal:

Thus, in providing this record, we are laying the foundation for the conditions through which the record of participants’ precariousness can be folded into future housing-related policymaking processes involving affordable housing for low-income older adults. (Wyndham-West, Odger et al. 2022: 599)

These two examples highlight how the participation of PWLE is endorsed (and claimed by the authors) but does not appear to extend or advance participation to domains such as involvement, collaboration or empowerment (International Association of Public Participation 2018).

2.2 Lived experience participation

Our review of the literature sought to uncover concrete examples of participation and the degree of influence PWLE were able to exert. This sharpening of focus in both the scoping review and focus groups was influenced by the LELs, who stated that one can participate, have a voice, or be heard, but change is unlikely without influence (also reported by Constantine 2023; Phillips and Kuyini 2017). Instead, the LELs argued that PWLE should have equality of opportunity in a range of areas, including decision-making authority. Consequently, the team adapted the original research question, added further sub-questions, and reviewed and analysed the literature to consider the:

- *nature* of the participation—including the type of involvement, such as consultation, advisory, steering, leader, leadership team, co-author, peer researcher, co-design, co-producer.
- *extent* of the participation—including level of involvement, such as once-off consultation, workshop attendance, annual committee meetings, regular commissioning activities.
- level of *agency* and autonomy enacted by or available to PWLE—including who holds power; if PWLE have the authority to create and define their roles and responsibilities; if PWLE are considered and treated as equal members of the project; leadership roles.

We expanded the level of agency and autonomy by considering whether it represented low, medium or high levels, and compared it to the IAP2 Spectrum (International Association of Public Participation 2018), as shown in Table 3.

Table 3: Levels of agency and autonomy

Level of agency and autonomy	Characteristics
Low-level	<ul style="list-style-type: none"> • Consultative or advisory functions that are ad hoc, once-off or infrequent. • PWLE have limited or no agency or autonomy. • Corresponds with Inform and Consult on the IAP2 Spectrum.
Medium-level	<ul style="list-style-type: none"> • Membership of committees, advisory boards and co-design projects. • Providing feedback regularly or in an ongoing capacity. • Some (yet often limited) attention to the agency, autonomy, authority, influence and power of PWLE. For example, PWLE may have been involved in co-design projects or lived experience forums, but oversight and control was maintained by policy makers, funders, or service provision organisations. • This level of participation aligns with Consult' and Involve spheres of the IAP2 Spectrum, with some examples suggestive of elements of collaboration.
High-level	<ul style="list-style-type: none"> • Detailed examples of PWLE leading or being involved in leadership teams and projects. • Extensive, ongoing and frequent participation by PWLE. • Lived experience roles framed as equal to non-lived-experience roles. • PWLE exercise autonomy and authority in defining and naming their roles. • In relation to the IAP2 Spectrum, these activities reflect Empowerment and Collaboration (and some elements of Co-production).

Source: Authors

In our scrutiny of the literature for the nature of involvement, the *extent* of participation and the level of *agency and involvement*, we identified:

- nine sources represented low-level participation: four peer-reviewed and five grey literature
- seven sources demonstrated medium-level participation: one peer-reviewed and six grey literature
- nine sources indicated high-level participation: four peer-reviewed and five grey literature.

Low-level participation

We share examples of low-level participation to ground this discussion, and also to draw attention to the nature and extent of the participation. The City of Mandurah (2021) consulted PWLE to better understand homelessness in the jurisdiction (which falls under the *nature* of participation). Similarly, Shelter Tasmania (2015) consulted PWLE to develop a consumer engagement strategy (*nature* of participation). Both activities involved once-off or ad hoc consultations (*extent* of participation), to guide or inform the development of strategies (level of *agency and autonomy* available to PWLE).

Despite claiming the inclusion of lived experience perspectives in the consultations, the participation of PWLE is reported as being a *'guide in the development of this strategy'* (City of Mandurah 2021: 8) and to *'provide a platform to develop principles for engagement and a conceptual model of consumer engagement'* (Shelter Tasmania 2015: 5). Although both examples express a commitment to inclusion and participation, the nature, extent and level of agency and autonomy was predetermined and controlled by the organisations, which means that the PWLE had little opportunity to influence or determine how they participated. While not diminishing the significance of participation, we are reminded of the lived experience advocate Margaret Doherty's ideas related to the *'seduction of inclusion'*, which position PWLE as making choices about participation, as she notes: *'it is often tempting to be the compliant representative, the one who readily agrees to the positions put by the "real" experts in the room—the professionals who represent the service provider'* (Doherty, McGuire et al. 2021:50).

Medium-level participation

Examples of medium-level participation include The City of Austin Innovation Team (Veda n.d.), which established a homelessness advisory committee (*nature*) to assist in generating research tools, provide consultation services and explore solutions to homelessness. Another example is Brisbane Youth Services (Penton 2021) which engaged in co-design (*nature*) with young people to develop the organisation's website and service delivery approach. The City of Austin advisory committee started as a pilot program and reported ongoing meetings (*extent*), while the Brisbane Youth Service commissioned a once-off co-design project (*extent*) (Penton 2021; Veda n.d.).

While these examples are different in the nature and extent of lived experience participation, both activities had oversight from third parties (*agency and autonomy*). Although both examples represent an increased level of commitment to participation, the overall nature, extent and level of agency and autonomy was predetermined by organisations rather than by PWLE enacting agency. While acknowledging the importance of initiatives such as advisory committees and co-design projects, we draw attention to the limits to agency and autonomy available to PWLE in such activities. Further, these and similar examples of medium-level participation are suggestive of the spheres of consultation, involvement and some collaboration on the IAP2 Spectrum (International Association of Public Participation 2018).

High-level participation

Lastly, we present examples of high-level agency, autonomy and participation. Shelter WA (2024) developed a consumer engagement framework and a toolkit (*nature*) promoting service user engagement. Murinas (2017) established an independent evaluation service run by PWLE (*nature*). Shelter WA (2024) projects included PWLE co-authoring a consumer engagement framework and co-designing and delivering training associated with a toolkit (*extent*). Murinas' (2017) group co-designed and delivered a service evaluating good practices for organisations who work with PWLE experiencing social disadvantage, including homelessness (*extent*). While these activities differ in nature and extent, both projects were led, designed and delivered directly by PWLE.

These examples highlight how lived experience participation can go beyond including lived experience perspectives and limiting participation with predetermined organisational parameters. Instead, high-level participation examples demonstrate how participation can involve lived experience positions of power, authority, leadership, co-creation, delivery, implementation and influence. The examples of high-level participation reflect the spheres of empowerment in the IAP2 Spectrum (International Association of Public Participation 2018). We would also make an addition to the IAP2 Spectrum: to include Co-production and User-led initiatives.

Our analysis revealed the varied forms of participation including the nature, extent and level of agency and autonomy. Deeper analysis revealed that low-level participation highlighted the seductive nature of including participants from marginalised backgrounds, where any participation is accepted and desirable (Doherty, McGuire 2017). While medium-level participation highlighted more commitment to consider the nature, extent and level of autonomy and agency, this still sat within the control of organisations that predetermined and limited the participation. Lastly, high-level examples demonstrated how lived experience participation can extend and elevate the participation of PWLE to positions of increased power, autonomy and influence.

2.3 Conditions and challenges

This section discusses the conditions for meaningful lived experience participation, and the challenges involved. Ten sources discussed the conditions and challenges associated with lived experience engagement and participation. Subsets of this theme include:

- recruitment
- consistent engagement
- relationships between PWLE and organisations
- conducive working environments
- conditions.

Drawing on our conceptualisation of participation as detailed in Section 2.2, we found that the literature addressed the conditions and challenges related to the *nature and extent* of participation, but rarely considered conditions and challenges associated with the level of *agency and autonomy* of PWLE. Our review results suggest that organisations and researchers may not be considering the conditions and challenges inherent to advancing levels of agency and autonomy. The degree to which the literature addressed conditions and challenges varied, with some sources providing extensive detail and others briefly noting these factors.

A few examples ground this discussion further. A UK-based initiative (Coleman, Byrd et al. 2017) aimed to support communities impacted by homelessness and alcohol and other drugs by positioning community residents with lived experience as ‘community champions’ (2017: 5). Each community established a Core Community Improvement Team, comprising community champions (PWLE living in the area), formal leaders (for example, business, public health, service delivery and healthcare leaders), and community connectors (people who served in a connector role). The report by Coleman, Byrd et al. (2017) details the recruitment, engagement and participation processes for community champions, as well as the conditions and challenges related to participation. Various conditions and challenges were listed, such as limited organisational resources, team cohesion, and concerns about how to approach and engage with community champions (Coleman, Byrd et al. 2017). Community champions also reported on conditions and challenges such as learning how to represent themselves, guiding teams, ensuring accessible language, organisational structures and histories, and being singled out as the team member designated to speak for PWLE (Coleman, Byrd et al. 2017).

Darren Murinas (2017), CEO of Expert Citizen, resisted the common challenges reported by other sources, particularly those that suggested recruitment and engagement with PWLE is difficult. Murinas provided a different perspective on the apparent challenges, redirecting the gaze from PWLE to organisations and practitioners:

We challenge the idea that people with lived experience are ‘hard to reach’ or that they ‘don’t engage’. Actually, sometimes we don’t try hard enough to ask them. Another way to think about ‘hard to reach’ is that the organisation saying that has ‘insufficient skill’? We’ve not always been successful in our bids to make things happen. Some doors have stiffer hinges than others, but we keep knocking and pushing. (Murinas 2017:3)

These quotes highlight that conditions and challenges commonly suggest that the difficulties stem from PWLE. However, this disguises the responsibility and actions of organisations, governments or researchers.

2.4 Impacts of lived experience participation

Given the influence of the LELs in this project—who emphasised the need to ascertain influence as well as participation—we scrutinised the literature for examples of how PWLE influenced decision-making, outcomes and change. While we identified examples of levels and forms of participation, it was harder to detect influence and associated outcomes.

At the outset, we recognised that this may be due to several factors, including influence and outcomes that occurred but were not reported, or that the influence of PWLE was not a priority or area of focus. This raises the question of whether the participation of PWLE extends to influencing policy, service design and practice—and, if not, why not?

Influence is key to the IAP2 Spectrum, with information and consultation not influencing decision-making, while further along there is an indication of increased levels of commitment to incorporate the advice from PWLE or put the decision-making in their hands (IAP2 2018). Consequently, the team reviewed and analysed the literature for instances of influence and outcomes related to the participation of PWLE.

We found that many sources claimed that the participation of PWLE led to influence, however the specifics are rarely detailed. One example described the influence of a Lived Experience Advisory Group:

Our members have influenced commissioning within Camden's Adult Housing Pathway, shaped our understandings of trauma-informed support, co-designed our camping for Multiple Disadvantage Day July 2020, and co-produced an action experiment addressing barriers to accessing mental health support for people experiencing multiple disadvantage. (Singles Homeless Project n.d.)

While this example suggests outcomes resulting from the advisory group's activities, the level of influence and impact of the outcomes is unclear.

Another example suggestive of influence is the UK-based initiative, *100 Million Healthier Lives: Spreading Community Accelerators through Learning and Evaluation* (SCALE) (Coleman, Byrd et al. 2017). The project was introduced in Section 2.3, along with a description of the community champions. It is reported that over an 18-month period, 64 community champions were positioned as respected team members and were engaged as partners and leaders in co-designing responses and solutions (Coleman, Byrd et al. 2017). The community champions had agency and autonomy to design and implement their role (Coleman, Byrd et al. 2017), which is reflected in the diverse ways each person conceptualised their role. For example:

- a voice of lived experience
- community stewards
- leaders already at work in their community
- knowledge holders
- learning from and giving voice to community residents
- change-makers
- cultivators
- bridges to social groups
- serving one's community (Coleman, Byrd et al. 2017).

These examples suggest that PWLE had some influence in role definition and scope.

We have found limited information on the outcomes resulting from the participation of PWLE. Like influence, it is unclear whether this is because there are few outcomes to report, or whether the outcomes have been omitted from the documents reviewed. Many of the sources listed activities such as PWLE co-producing government reports, providing feedback and recommendations to service providers, or co-designing projects. However, there are very few reported outcomes of this participation.

3. 'Do we have a voice?'

Experiences of participation

- Participants universally reported that being able to participate and influence policy, service design and practice is far removed from their everyday lives and realities.
- People with lived experience reported high levels of stigma resulting from their experiences of homelessness and housing precarity. Consequently, people feel unseen, unheard and disempowered.
- The concept of structural violence is applied to capture the pervasive reports of encounters with services, systems and workers that were unsafe, transactional and confronting. The concept extends to include the resulting impacts of participants feeling blamed, stigmatised, judged and disrespected.
- Lived experience and expertise has the capacity to improve policy, service design and practice and undermine disempowerment, stigma and exclusion, reinforcing the significance of PWLE having a say in matters that directly affect their lives.
- Developing and expanding a lived experience workforce would demonstrate the range of roles PWLE could fulfil, while recognising the importance of diverse lived experiences and expertise and equitable remuneration and working conditions.

Analysis of the six focus groups uncovered four major themes:

- Unseen, unheard and disempowered
- Structural violence
- Lived experience participation and influence
- The lived experience workforce.

As a project that has embedded lived experience methodology, the research team has attempted to represent the perspectives of PWLE accurately and authentically. This means we extensively share quotes from PWLE. We recognise that one limitation of the project is that there were insufficient resources to systematically include the perspectives of policy and service provider and practice stakeholders. However, we believe holding and creating space that privileges the views and experiences of PWLE is an important first step in understanding the principles, frameworks, models and strategies that enable lived experience participation in housing and homelessness policy and service design (Research Question 2).

3.1 Unseen, unheard and disempowered

Homeless people ... they're frowned upon, they're looked down upon. The individual is not considered. They fall on hard times for many reasons. They will judge you and they'll categorise you.
(PWLE)

Overwhelmingly, focus-group participants communicated enduring experiences of being unseen, unheard and disempowered. Characteristics of this central theme included being disregarded, feeling that services did not care, and that the person's needs and concerns were not taken seriously. As one PWLE said: *'But you're talking about, "Do we have a voice?" No, we don't, because they don't care, and they don't listen.'* Participants consistently reported experiences of marginalisation based on assumptions and stereotypes about people who experience homelessness or who are social or public housing tenants. Participants pointed out that such experiences are disempowering and silencing. While participants did not use the term stigma to describe the pejorative assessments and judgements made by others about their homelessness and housing experiences, all shared accounts of the negative impact of these discursive constructions on their wellbeing and sense of self.

Regardless of housing status or experience, participants said that as PWLE they felt disregarded, invalidated and lacking legitimacy. This was reflected in one person's comment: *'You can ring and ring ... but they don't get back to you and you panic.'* Key to these experiences was the sense that communication was ignored, as one person said: *'Listening and doing something are two different things.'* Examples shared by participants in social housing included reporting issues such as broken fixtures and pest infestations and receiving no response for months, or expecting frail individuals to move household furniture on their own. Participants argued that respect involves recognising the challenges PWLE have and do face.

Consequently, when asked about lived experience participation and influence, participants thought it aspirational. One participant said, *'Before you even ask of the opportunities, what will be the power given to me in order to be able to make those changes?'* So while this project sought to understand the evidence for, and principles, frameworks, models, and strategies that enable lived experience participation, participants argued that participation and influence are aspirational. Participants stated that given service users and PWLE struggle to be recognised and treated with respect, the idea of contributing to positive change is far removed from their lived realities.

These experiences were reported to manifest in reduced confidence, anger, frustration and for some, an unwillingness to participate, as previous contributions were not valued or did not appear to contribute to change. Despite this, some participants refused to accept the experience of being unseen, unheard and disempowered, arguing: *'You need to keep being the squeaky wheel.'*

3.2 Structural violence

I was a little gay boy in this huge complex [that was] all straight and scary-looking—absolutely terrifying. I didn't want to say anything, didn't want to do anything. It's terrifying ... lining up for the first time. I've just lost my house, or I've just been kicked out. When I started, I had no idea where to go, who to talk to. The first place I went ... they said come back in two weeks and we'll have an interview with you. I got anxiety and depression ... from that. I'm still learning to deal with it now. These places are not encouraging, they're not warm. They're sterile, they're cold. They're scary. (PWLE)

Underpinning the experiences of being unseen, unheard and disempowered were reports of unsafe, transactional and confronting encounters with services, systems and workers. Such experiences left participants feeling blamed, stigmatised, judged and disrespected:

Service workers should keep their opinions to themselves and out of earshot of the people that are walking in—especially when it has got to do with the actual people. So ... some people who were homeless and obviously had ... other issues didn't shower, maybe, except for once a year, and would drop their clothes off and the workers would come in with their tongs and parade around and talk about that person once they had left, not realising that we are all homeless and we probably all do smell to some degree. What you're [the workers] giving off is that you're better, and that, 'What I'm going to say, I'm going to say behind your back when you leave as well.' When you've been homeless for a while you lose all dignity and it's just another day going in there. I haven't showered for a week, and you don't care who knows or smells you from behind. But at the start, there's no sense of privacy, there's no sense of dignity. (PWLE)

These experiences were expressed in all focus groups and reinforced during the roundtable discussions, leading the team to draw on the concept of structural violence to account for this phenomenon. We draw on the following definition of structural violence to conceptualise the lived experiences shared with us:

*Structural violence is a construct that has been used to demonstrate the way in which **the political and economic organisation of society can invisibly and systematically foster physical harm and emotional distress among groups of vulnerable individuals. Integral to structural violence is the role of institutions and social practices in preventing such persons from reaching their full potential**, emphasising the capacity of the modern state to protect—or fail to protect—its citizens from large-scale forces of political economy and history. (Whittle, Palar et al. 2015: 4–5; emphasis added)*

This definition relates to the lived experience of participants in this research in several ways. First, we heard numerous accounts of emotional distress for PWLE when they were unseen, unheard and disregarded. Often, emotional distress resulted from the ways in which organisations arranged the delivery (or non-delivery) of services. The organisation of services was something of a mystery to PWLE, meaning there was limited transparency about services and decisions that impacted on service users.

Ultimately, the multiple experiences of structural violence inhibited service users from exploring or reaching their potential, and contributed to further harm and distress.

Participants shared their views on, and explanations for, experiences of structural violence, arguing that services appear to prioritise their own agendas and requirements, rather than the needs of consumers. These experiences reflect a service-centric approach rather than person-centred approach. As one participant noted: 'So, services need to have much more person-centred indicators, rather than how many people has the service seen in a day.' Similarly, participants reported that their experience of service delivery was often transactional, and rarely relational, with one participant requesting that services: 'Treat us like a human, not like an interaction.' The focus on service delivery objectives and funding-driven key performance indicators left participants feeling they needed to fit predetermined categories of need:

It's all paperwork. [They] don't just want to hear about your situation ... it's just like ticking boxes and ... not everybody fits into those categories. Everybody's different. Everybody's going through different things, or [is] in different circumstances. (PWLE)

Economic imperatives were identified by participants as driving service delivery and deflecting attention from the wellbeing of service users, with one person saying: 'The cost is more important than your wellbeing.'

It is unlikely that organisations intentionally set out to meet their own needs and agendas over those of service users, but the dominant and pervasive experience of participants was one of being secondary to the operations and focus of the organisations they sought assistance from, as noted by this participant:

You go to a service, they don't care about your purpose. They don't care about your goal. They care about: 'Have I provided my service that I'm obligated to give?' (PWLE)

Structural violence is also characterised by policy and practice siloes and 'unequal access to social systems of support like housing, health care, education and employment, primarily due to a long history of cuts to social welfare funding and programs that disproportionately affect women' (Milaney, Stacy et al. 2018: 561). These siloes can be conceptualised as a policy vortex where service users are caught between different policies, organisations and systems that rarely interact or communicate with each other.

Further, there is an expectation that service users navigate the siloes, despite conflicting and contradictory expectations and messages from the various systems. For one participant, navigating different government and non-government agencies was complicated and involved decisions made on her behalf without her input, and which resulted in housing debt due to damage by a perpetrator of violence, four years of couch surfing, and having her children removed by child protection authorities:

Can't get house for kids if not on Centrelink and can't get proper housing to house kids get stuck into shitty cycle ... totally unjust. (PWLE)

Commonly, participants reported navigating child welfare, housing, justice, health and mental health simultaneously. As one person said: 'No one is held accountable and there is a power struggle' and 'Instead of actually dealing with a problem ... they just pass the buck, pass it on, pass it on.'

Related to these discussions are one-size-fits-all policies which participants said manifest in service delivery patterns and practice approaches. These practices create structural violence through processes of exclusion and disadvantage (Magwood, Leki et al. 2019: 2). One participant noted: 'The individual is not considered ... They will judge you and they'll categorise you and ... it's very dangerous'. Similarly, poorly communicated policy changes were identified as creating significant and detrimental impacts, particularly for formerly incarcerated woman, with one noting: 'it's like a secret language—a secret club.' These accounts speak to the emotional, physical and administrative work (Murphy, Murray et al. 2011) undertaken by PWLE in trying to access and navigate services.

In the context of these experiences of structural violence and feeling unheard, unseen and disempowered, participants questioned the accountability of organisations in accepting responsibility for mistakes and neglect, as well as not acting on feedback from PWLE. This reflects ideas of structural violence as '*invisible, static, insidious, silent, taken-for-granted, and hidden*', involving '*unequal distributions of power, influence, and resources*' (Taylor 2014: 258), which is referenced in this quote:

Because there's a box in that reception area near the mailboxes that's got all computerised stuff to work the doors that break down all the time. You ring a number—this is where there's no transparency—what's the secret? I'd like to know what the secret is with this Housing. It seems to be a secret for some reason, because they'll put numbers on the board and say, 'Ring this number for this ...' and when you ring them up, an hour-and-a-half on the phone waiting, you get, 'Oh look, we don't handle that, here's another number, we don't handle that.' (PWLE)

Participants felt that experiences of structural violence highlighted unexamined assumptions by agencies and workers about deservingness, something women participants repeatedly drew our attention to:

I also noticed that there was a behavioural pattern in the sense of, 'If you're a good person, we [services] will help you and treat you kindly and you don't look to be on drugs, [or] have major mental disorders, so we're going to be kind to you ... and we're going to give you things on the side and maybe treat you differently, but we subliminally tell you that if you're a good girl we're going to help you more and those people out there that are ranting and raving won't get those needs [met] 'cause they've been homeless for too long and couldn't help themselves.' That's what I saw very quickly. I also saw that if you don't agree to certain services then we will not give you more service. (PWLE)

While participants provided diverse examples of what they perceived to be uncaring systems, organisations and workers, they also articulated their understanding and empathy for workers, saying '*Workers really get institutionalised, don't they?*' Discussions also focussed on the broader political and policy issues that impact practitioners:

But realistically the workers aren't interested, or they're overworked, or they don't have the training, I would say. It's a matter of everything combined, so I knew that I was playing against a system that didn't work for me. (PWLE)

3.3 The impact and scope of lived experience

I think it's really important that people like us and the many others that are experiencing or have experienced homelessness have a say in the way we move forward, and it's not coming from people in really nice suits ... that don't really have any experience. I think it's really important. (PWLE)

Despite experiences of structural violence, and being unseen, unheard and disempowered, participants asserted the far-reaching value of lived experience participation and influence. Participants argued that lived experience participation and influence improves policy, service design and practice and undermines disempowerment and structural violence. These arguments reinforce the significance of involving those directly affected to promote efficient and effective decision-making (Sanders and Stappers 2012; Szebeko and Tan 2010). It was suggested that collaborative practice involving PWLE in equal partnership with policy makers, service designers, providers and practitioners would maximise the contributions of all parties and lead to meaningful and practical ideas, strategies and solutions.

The focus groups and roundtable discussions both focussed on how lived experience perspectives would ensure satisfactory, effective and sustainable policy, practice and service design outcomes. Participants highlighted the importance of pragmatic approaches. The following quote from a focus-group participant who was currently experiencing homeless exemplifies the power of lived experience perspectives to create pragmatic and useful outcomes:

I was in hospital for a few days. When I came out, one of the community service people said, 'Oh, we can put you in a hotel for four nights.' And I said, 'Actually, the best thing I need is four new tyres on my van.' And they said, 'No, we can't do that.' The tyres would be cheaper than the hotel. But they said, 'No, we can't.' I've always said solutions don't have to be pretty, but they have to work. (PWLE)

Desire paths were put forward by one participant as an example of the utility of lived experience influence. Desire paths originate in urban planning and landscape architecture. They denote the alternative paths created by pedestrians, which offer a more direct, accessible or comfortable route to one's destination (see Figure 2). Within social sciences, desire paths are referred to as 'social desire paths' (Nichols 2014: 166) which indicate 'emergent phenomena that occur when individuals interact with formal social structures that are not working for them' (Nichols 2014: 167). Central to the discussion on desire paths was a principle that, while those not directly affected by an issue are usually well intentioned, their lack of lived experience hampers the design of relevant and practical solutions (Sanders and Stappers 2012; Slay and Stephens 2013; Szebeko and Tan 2010). Participants emphasised the need to be able to participate and influence through co-design, co-production and collaboration, arguing this would ensure that responses and solutions would accurately reflect the needs and perspectives of those with lived experience.

Figure 2: Desire path



<https://stock.adobe.com/au/images/heidelberger-platz-berlin-n-desire-path/482490214>

Reasons for not including lived experience perspectives were explored with participants, and they identified several factors, including hierarchies of knowledge, expertise and power relations. The following quote draws attention to the implicit ways power and ideas about knowledge and expertise manifest:

I was on a panel with CEOs of homelessness organisations [who] had a long time to prepare. I was asked one hour before: 'Would you like to be the lived experience voice on the panel in a Victorian conference?' So, was I paid the same? No. Was I given the same respect as everyone else? No. Was I given enough time to prepare? No. But did I deliver? Yes, I delivered. I showed up and I still was able to deliver. So, I think my expertise ... is just as valid as anybody else's. (PWLE)

Linked to hierarchies of knowledge and expertise is the issue of qualifications. The participants who identified as lived experience advocates described facing barriers and, at times, discrimination, from those with formal qualifications, reporting that lived experience is constructed as inferior to formal training and education. However, for PWLE, the lived expertise developed from marginalisation and discrimination is a source of personal power and a legitimate form of qualification (Faulkner 2017; Mahboub, Martin et al. 2023; Newman, Boxall et al. 2019).

Participants argued for the recognition and dismantling of hierarchies of power, expertise and knowledge between those with formal qualifications and those with lived experience, stating: 'We can see the gaps, because we've lived through the gaps.'

Active application of co-production principles of reciprocity, mutuality, shared knowledge, distributed leadership and peer support (Slay and Stephens 2013) would help reduce power differentials between those with and without lived experience. Power sharing was characterised as 'dropping the usual way of doing things'. These ideas extend to leadership, genuine collaboration and partnership:

Lived experience [is] ... working ... as a team ... working together ... and like ... the managers or the workers ... they should be 50/50 ... where everyone's on the same page ... not there just getting the money but actually want to help and change ... and work together. (PWLE)

Participants emphasised the value in reciprocal learning and teaching between practitioners, policy actors and PWLE, noting that PWLE are commonly motivated by 'paying it forward' for the benefit of others experiencing disadvantage and discrimination. This issue of passion and commitment was picked up by participants, with one saying: 'Whether I get this right or wrong ... there's so much more at stake than just money.' The comment reflects the greater investment and commitment participants articulated, and which they felt separated them from practitioners whose knowledge base rested on formal qualifications and work experience. This points to perceived differences in motivation for working in the housing and homelessness sectors between people with and without lived experience.

3.4 The lived experience workforce

Having someone who's actually been through that and can actually then describe what navigating systems means to someone coming in could be a really useful way to employ someone in homelessness services. (PWLE)

Focus-group participants emphasised the need for the development and expansion of the homelessness and housing lived experience workforce. Three elements underpin this theme: the range of roles, diversity and working conditions.

Range of roles

Participants argued that there were many paid roles that PWLE could fulfil. These included peer workers, liaison, 'conduit', 'conductor', systems' navigator, and knowledge sharer. Key to these roles were equal pay and conditions (which are discussed in more detail in Section 4.2) and being recognised for expertise of equal value to other team members without lived experience. The role of systems' navigator was seen as key to orienting people to services, providing support, role-modelling recovery and healing, and explaining the policies and procedures of a service:

But I think if there were people that were around with lived experience that could somehow get in contact with people like me at that time and say, 'Look, mate, you don't have to go down this path, you don't have to live this kind of life, there's another way.' (PWLE)

Being a member of a lived experience workforce was considered to create the conditions for empowerment, confidence building, healing and recovery, and to also provide meaning and purpose in relation to difficult life experiences. These ideas speak to activities and actions that would likely counter the theme in Section 2.1 of PWLE feeling unseen, unheard and disempowered because of the stigma associated with their experience of homelessness or housing precarity.

Diversity

The issue of ensuring diversity in the lived experience workforce was important to participants, who argued that different experiences were more likely to meet the needs of service users:

Say for example you're going to set up ... a consumer advisory group ... you need to make sure it's actually representative and that goes in the selection process [and] ... the recruitment process, ... your interview process and selection. You need to get as wide a lived experience as possible, otherwise it's a bit pointless if they're all 30-year-old white guys. (PWLE)

While participants recognised that not every unique experience of homelessness or housing precarity could be represented in a lived experience workforce, they argued that the complex issue of representation needed regular attention:

You ... just have to work hard, you know, and make sure ... no one is left out or not understood, and have the time and the patience to actually, you know, work with them and ... go step by step. (PWLE)

Working conditions

In relation to workforce conditions, participants argued for parity:

For me it's more than recognition. For me, it's being valued and [getting the] same pay rate: 100%. It's extremely important to ... be seen ... exactly the same, because I think once you start putting differences in, there is the problem. It shouldn't be any different ... because what about the person that doesn't have lived experience, but is damn good at their job? (PWLE)

Aside from parity in working conditions, participants highlighted that: 'We dip into our trauma for our job', noting that this can have impacts on the person and involves degrees of emotional labour. This is a theme that we explore further in Chapter 4.

4. Policy and practice development options

- **To move from aspiration and intent, significant cultural shifts are required for PWLE to participate and influence housing and homelessness systems, organisations, policies and practices.**
- **The most significant change needed is an overt and explicit rebalancing of current power relations, with lived experience placed at the centre of all policy, practice and service design.**
- **Several conditions must be met for lived experience participation and influence to gather momentum: funding of lived experience initiatives; the basic human right of safe and affordable housing; people with lived experience being seen as equal citizens who are treated with decency and respect.**
- **A set of co-designed principles, conditions and practical strategies would offer a roadmap for policy and practice development options.**

When it comes to lived experience, one of the biggest failings I see is what lived experience means for policy. (Stakeholder)

The research teams in South Australia and Victoria presented the emerging findings from the scoping review and focus groups to PWLE and policy, practice and academic stakeholders. Some stakeholders identified as peer workers, or as having both lived and professional experience and knowledge, which highlights intersecting identities. Participants reflected on the emerging findings, and then worked collaboratively in small groups to propose policy and practice developments that could advance lived experience participation and influence in the housing and homelessness sectors.

In bringing PWLE and professional stakeholders together, the research teams in each jurisdiction paid careful attention to the structure and process of the roundtable discussions. The teams were mindful of messages participants had communicated in the focus groups and wanted to counter this by demonstrating commitment to valuing and centring lived experience. This meant that the enduring theme of being unheard, unseen and disempowered, along with experiences of structural violence, informed the team in their planning of the roundtables and their facilitation of the conversations. The presentation of the emerging findings avoided academic jargon or inaccessible language—a lesson the academic members of the research team had learnt early on from the LELs.

We warmly welcomed participants to the events, provided refreshments and food, created space for participants to connect, and ensured that PWLE had multiple opportunities to share their views and ideas. The Victorian roundtable included more PWLE than other stakeholders. Both roundtables created space for what Eve Tuck calls desire-based research approaches where the *'hopes, the vision, the wisdom of lived lives and communities'* (Tuck 2009: 417) were privileged and honoured. Stakeholders respectfully engaged in the space by listening to and valuing lived experience perspectives.

Chapters 2 and 3 of this report have highlighted that there is limited evidence on (or about) lived experience participation and influence in housing and homelessness. Roundtable discussions confirmed these findings, as captured in this quote:

We are a long, long way from that [lived experience participation and influence]. Baby steps that agencies are taking at the moment to engage. [It] is just the first stage of a process. (Stakeholder)

We have previously reported in Chapter 2 that the meaningful participation and influence of PWLE is mostly aspirational in the homelessness and housing sectors. It appears that to move from aspiration and unfulfilled intent requires cultural and paradigmatic shifts in housing and homelessness systems, organisations, policies and practices. Given this, the roundtable participants were asked to suggest pragmatic first steps to move from the aspirational lived experience participation frameworks (which are a first step signifying intent) to practical action where PWLE have genuine influence and authority. The roundtable participants universally argued for a rebalancing of current power relations, with lived experience placed at the centre of all policy, practice and service design, and extending to decision-making influence.

However, there are some caveats on this proposal. Fundamental to lived experience participation and involvement is addressing and meeting basic needs and human rights. Participants noted that lived experience participation would be unlikely to gather momentum or contribute to significant influence or change unless:

- there was sufficient funding to meet the basic human right of adequate, safe and affordable housing
- PWLE were viewed as equal citizens and treated with decency and respect.

This is particularly the case for those currently experiencing homelessness or housing precarity—their capacity to participate and influence is mediated by their crisis circumstances. It is important to note that this does not mean individuals cannot participate or influence while experiencing homelessness or housing precarity—but that their capacity to do so is mediated by their foremost focus on safety and security.

If we consider the following participant's experiences, we can see how engaging in participation and influence activities would not be their highest priority, although it does not completely preclude them from participating or having a say:

This is where I don't understand. I didn't have anything, and it was winter, and I was freezing, and I had a massive dog in a really small car. One of the reasons I stayed homeless is because I either had to kill my dog or give my dog up and I couldn't do either because he was my saviour. So, I lived in that car. At that time, I was freezing and gave whatever blankets I could to my dog. He got so sick 'cause it was so cold. I managed to find him a place. But in that time, I ... was not offered a sleeping bag, I was offered nothing in the middle of winter. I contacted another place that I saw on my hours of scrolling and asked for a sleeping bag and a tent to be sent to me and it was sent to the service provider that never gave it to me. (PWLE)

Participants argued that minor changes to housing and homelessness policy and systems would contribute to iterative, short-term and small-scale change. It was asserted that reimagining and rebuilding housing and homelessness policy mechanisms and systems was required, based on the participation, influence and leadership of PWLE. In other words, cultural change was required.

Despite the policy and practice intent and interest in embedding lived experience and expertise, there has been limited action by governments and housing and homelessness organisations locally or internationally. Participants in this study argued that the root cause of this inaction is the stigmatised and marginalised identity ascribed to people who have experienced homelessness and housing precarity. As a consequence:

- co-designing policy and services with PWLE is aspirational
- consumer feedback is 'a waste of time' as there is no evidence it informs or changes policy or practice
- the value ascribed to lived experience and expertise is unknown.

This report documents and provides a blueprint to further incorporate the expertise of PWLE in policy and practice developments.

This study breaks new ground by exploring the views of PWLE on their capacity to participate in and influence housing and homelessness policy, practice and service design, as there are few studies considering these activities. This highlights the need for greater evidence, exploring the perspectives of policy makers, service providers, practitioners, and a broader range of PWLE. Such research would build on this report, providing a more comprehensive picture of the challenges and opportunities that other stakeholders face.

Many policy and practice stakeholders are committed to and passionate about the meaningful participation of PWLE. This theme was repeated when stakeholders learnt about the project, when they referred participants to the study and when they contributed to the roundtable discussions. However, they did not know where to start, and did not want to perpetuate structural violence. Further research will assist in testing out the recommendations proposed by PWLE in this research.

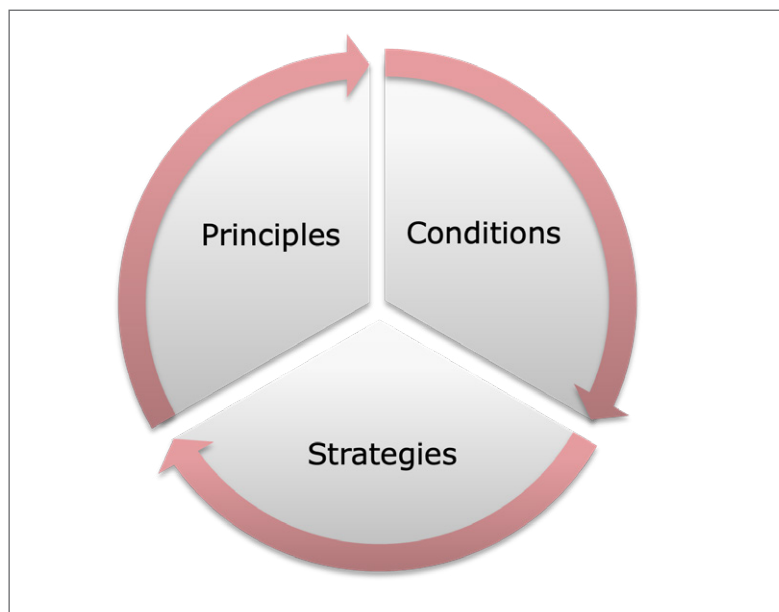
However, further research is insufficient without practical, funded action.

Analysis of the roundtable data indicates three considerations for cementing lived experience expertise and knowledge in policy, service design and practice development (as shown in Figure 3):

1. A set of principles are required that enable lived experience influence and participation.
2. The principles must be underpinned by conditions that enable influence and participation.
3. Practical strategies are proposed to advance the participation and influence of PWLE in housing and homelessness policy, service design and practice.

These principles, conditions and strategies were co-designed by and with roundtable participants. They were then collated and synthesised, and shared with participants. The participants provided feedback and endorsement, which indicated a degree of trust in the proposals for policy and practice development.

Figure 3: Advancing lived experience participation and influence



Source: Authors

4.1 Principles for lived experience participation and influence

Seven principles for lived experience influence and participation are outlined below.

1. **People with lived experience are recognised as having the capacity and the right to act and decide independently.** PWLE are capable of meaningfully contributing to decisions that affect their lives, regardless of their housing or homelessness status. This principle recognises that participation and influence are a right that is not typically afforded to many PWLE—but which is a fundamental requirement.
2. **Lived experience is recognised, developed and promoted as a discipline, with equally valid claims to qualification, expertise and specialist knowledge.** This principle builds on areas such as Mad Studies (Faulkner 2017), where the practice and study of lived experience—in this case in housing and homelessness—is considered a discipline within its own right.
3. **Peer support between people with lived experience is valued and supported.** Recognising and supporting the value of peer support mechanisms and activities is an element of co-production (Slay and Stephens 2013) and a critical feature of trauma-informed approaches (Substance Abuse and Mental Health Services Administration 2014).
4. **People with lived experience and expertise identify and lead research agendas.** This principle underpins co-production, with PWLE exercising the ability to identify research gaps and agendas and subsequently lead implementation of research activities.
5. **Lived experience and expertise perspectives are systematically embedded in housing and homelessness policy, service design and practice.** Research and roundtable participants proposed this principle to create the conditions for genuine lived experience participation and influence. Participants argued that ‘tinkering at the edges’ to incorporate or establish lived experience would not produce the change required. Building on the theme of structural violence reported previously, this major change requires accountable and transparent recognition of systems, practices and cultures that can work against the interests of those they were designed to support.

6. **Structural violence is acknowledged and not re-enacted.** It is important for governments, policy actors and organisations to accept responsibility for policies and practices that harm, exclude, silence, disrespect or invalidate PWLE. This acceptance of responsibility includes apology and assertive commitment to not re-enact structural violence in any form. This principle requires the commitment and leadership of those in senior positions, frontline practitioners, middle managers and researchers (who while not identified in this project as enacting structural violence, were just as likely to do so).
7. **Collaboration and co-production are emphasised to produce a transdisciplinary approach that merges lived and non-lived expertise.** This principle highlights the importance of collaboration and shared power between those with and without lived experience. Such an approach creates the conditions for transdisciplinary knowledge and practices that transcend siloed ways of knowing, doing and being.

4.2 The conditions for lived experience influence and participation

Several conditions are required for influence and participation by PWLE. There is considerable emotional labour involved for people sharing lived expertise, and this must be recognised in a non-pathologising manner (Faulker and Thompson 2023). There are impacts and strengths associated with—and developed through—lived experience of structural violence, disadvantage, exclusion, violence and trauma. It is also recognised that meaningful and purposeful lived experience roles and employment opportunities contribute to recovery and wellbeing (Byrne, Wang et al. 2021; Phillips and Kuyini 2018). The following seven conditions enable this approach.

1. People with lived experience are inducted and trained for lived experience and expertise roles. The training is ongoing, trauma-informed, and designed and delivered by PWLE.
2. Communities of practice are established by and for PWLE to share experiences, ideas and support. This may include formal and informal opportunities for debriefing and ‘*decompression*’ (PWLE).
3. People with lived experience are always remunerated for their contributions. This remuneration should reflect parity with rates within the organisation—that is, parity between staff with lived experience and non-lived-experience—and payment benchmarks in other sectors where lived experience workforces are more developed.
4. Transparency, accountability and open communication are key conditions between PWLE and stakeholders with non-lived-experience. This includes clarity about roles, tasks and activities, the intended length of the role, remuneration and other conditions.
5. A minimum of two PWLE work together on any task or in any setting. This condition ensures a range of lived experiences and perspectives, and ensures that opportunities for peer support are built in.
6. Opportunities for PWLE to develop expertise, leadership abilities and other capabilities are made available and based on the recognition that PWLE, like their colleagues with non-lived-experience, represent different levels and forms of capability and competence.
7. In addition to a peer-led community of practice, lived-experience-specific supervision by and for PWLE is available.

Relationships between people with and without lived experience—service providers, policy and other stakeholders—are central and based on mutual respect, reciprocity and active attention to power differentials.

4.3 Strategies to advance lived experience participation and influence

The principles and conditions outlined in sections 4.1 and 4.2 provide a guiding framework for lived experience participation and influence. The strategies listed below offer suggestions for policy and practice development and actions.

1. Develop, implement and monitor transparent policy and practice mechanisms that account for the ways in which lived experience feedback is utilised and incorporated in policy, service design and practice settings.
2. Invest in the development of the lived experience workforce.
3. Co-design and implement lived experience standards.
4. Establish lived experience panels.
5. Fund the development and operations of a lived experience union.
6. Create and fund Lived Experience Commissioner roles.

Each strategy is now explored in more detail.

4.3.1 Develop, implement and monitor

This strategy reflects the ideas presented in focus groups and roundtables, where participants emphasised that even when they had provided feedback or input through lived experience participation strategies, they had little confidence that their ideas were heard or acted upon (also found by Phillips and Kuyini 2018). Participants felt accountability was missing, and this led some participants to state that they would not continue to provide feedback, because they lacked trust in the process or outcome. We also note that we found few instances of influence or outcomes reported in the literature.

PWLE consistently expressed their despair and frustration that their feedback and input seemed to land in a void, with one person saying they believed their '*constructive comments*' ended up in the '*bins*'. These comments ranged from service-level feedback mechanisms often involving a suggestion box (or the digital equivalent) through to contributions to policy or other consumer consultation mechanisms—including advisory groups. Participants reported that they had no idea if they had been heard, or anyone had acted on their feedback (this was also reported by Constantine 2023, who noted that positive feedback is commonly accepted and reported by organisations). Consequently, the first strategy is to develop, implement and monitor transparent and accountable mechanisms in policy and practice that report on how lived experience and service user feedback is utilised and incorporated.

4.3.2 Invest in the development of the lived experience workforce

Investing in the creation of a homelessness and housing lived experience workforce was discussed in Section 3.4. We noted then that there are a wide range of roles and responsibilities that PWLE could fulfil, and which include and go beyond peer work. Importantly, a lived experience workforce needs to create leadership roles in areas such as research, policy, education and practice. We also note emerging results from the On Our Own Terms (2024) lived experience leadership project (Cataldo, Martin et al. 2024), which has explored literature on lived experience leadership. That project's initial findings identify that lived experience leadership exists both inside and outside organisations and institutions, and navigates issues of representation and loyalty to lived experience communities in highly complex environments (Cataldo, Martin et al. 2024).

Building a lived experience workforce requires access to a range of developmental opportunities for PWLE, many of whom have experienced disrupted education. Opportunities for formal qualifications should be available to PWLE, ensuring they have career pathways beyond lived experience roles, and which offer a range of possibilities for influence and leadership. A lived experience housing and homelessness workforce would encompass many of the principles and conditions previously discussed in this chapter and would be a safe, supported and supportive space characterised by equal working conditions that ensure retention (see the 2021 work by Byrne, Wang et al. on mental health lived-experience workforce frameworks).

4.3.3 Co-design and implement lived experience standards

This strategy relates to co-designed lived experience standards for the housing and homelessness sectors, and involves recognising that many service users have experiences of intersectional and structural oppression. This highlights that PWLE should have choice and autonomy about their level of participation. These standards would position PWLE in co-leadership roles and focus on meaningful participation and opportunities to influence.

The principles and conditions proposed in sections 4.1 and 4.2 would form a basis for the development of the standards, which should consider other lived experience frameworks and build on them to ensure relevance for the housing and homelessness sectors.

The standards would be active and operationalised in a range of ways. One proposal was using the standards to audit policy, service and practice compliance with activities that promote meaningful lived experience participation and influence. This would necessitate training for organisations to understand their responsibilities within the standards and their responsibilities towards PWLE. Audit activities would be undertaken by a panel involving equal representation of PWLE, funders and independent service provider representatives from other organisations. Each stakeholder (including PWLE) would have equal and independent decision-making authority. Training for the panels would be required. Unwaged members of the panel would be paid sitting fees reflective of other lived experience areas, such as mental health and family violence. Services not meeting the audit standards would be provided with advice, and given the opportunity to address and rectify identified issues. If a service did not adequately rectify or remediate issues identified through the audit, funding bodies would introduce financial penalties.

4.3.4 Establish lived experience panels

Lived experience panels would work collaboratively with stakeholders to inform governance processes and practices, service design and delivery, policy and procedures. Lived experience panel members would have equal and independent decision-making authority and be appropriately remunerated for their contributions.

To ground this strategy, we share an example from a roundtable discussion. The issue of the behaviour of residents in shared residential facilities (such as rooming houses) was raised. It was proposed that the usual way of responding involves staff deciding how to manage the issues—which rarely provides satisfactory outcomes (desire paths come to mind here, and the need to involve those with experience of the issue in decisions). In this example, the lived experience panel would work collaboratively with the staff to identify solutions and responses. Ultimately, the panel might come to the same decisions as the staff but—reflective of the lived experience principle of ‘nothing about us, without us’ (Charlton 1998: 14)—more authentic and useful responses are likely when those with direct experience of the issue are involved (Sanders and Stappers 2012; Szebeko and Tan 2010). Importantly, the work of the lived experience panels would be subject to the same expectations of other stakeholders, such as confidentiality and professional behaviours.

4.3.5 Fund the development and operations of a lived experience union

The strategy of supporting the development and operations of an independent lived experience union or independent body was firmly endorsed by roundtable participants and raised in several focus groups. Participants argued that the union needed to encompass a range of lived experiences, and should recognise that most people have intersecting experiences of disadvantage and marginalisation. The union would have several roles and functions, and require funding to establish and operate. It would be established and administered by PWLE.

By their very nature, unions are bodies that have membership from and represent the lived experience of people—typically paid and voluntary workers in particular industries or occupations. The spirit of unionisation already exists in the housing arena. For example, the Tenants Union of Victoria (now Tenants Victoria) was established in the 1970s, largely due to the work of activist tenants. The Tenants Union has been instrumental in connecting tenants' rights with consumer rights, providing legal advice, and contributing to legislative change—including the establishment of the Residential Tenancies Act of 1980 (Tenants Victoria n.d.). Some social housing associations also have tenancy advisory groups (e.g. Unison Housing). While these are not unions, they include lived experience participants who represent the interests of renters and are involved in decision-making. However, there is currently no union or similar body to Tenants Victoria that represents and supports people with lived experience of homelessness.

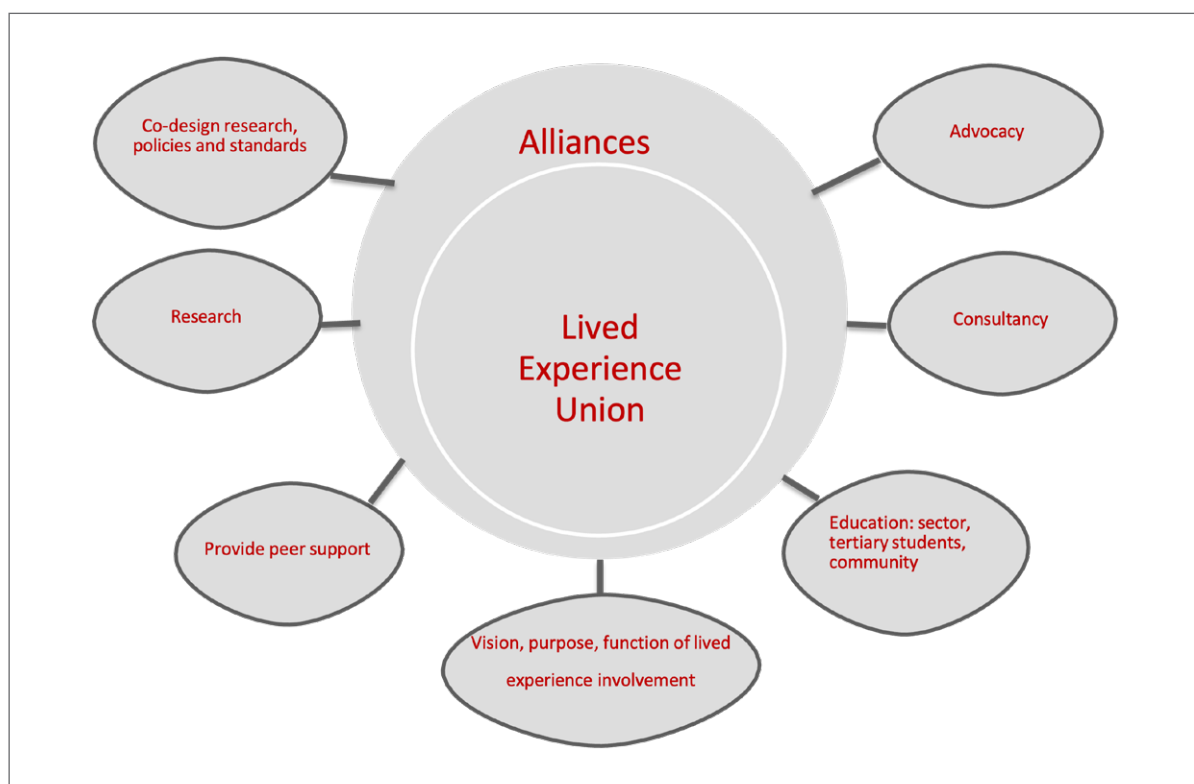
Details about how a lived experience union would function would be premature at this stage, as it would require careful preliminary work involving the leadership of PWLE to clarify its purpose. Nevertheless, once the purpose of the union is established, the process could then shift to key considerations such as membership, vision, values and goals. Following this, a model could be developed that included guidelines, such as terms of reference and operational procedures that explain how the union would function, including roles, responsibilities, relationships and sustainability.

Possible work that the union could undertake—with the proviso that the lived experience membership would ultimately determine the activities to be undertaken by the union—might include:

- advocacy and consultancy to government, industry and other stakeholders
- input into the development of service sector practice guidelines
- research and education co-design and co-delivery
- building a network of alliances.

Additionally, the union would be available to stakeholders for consultancy, education, research and co-design activities, including providing lived experience members for staff recruitment panels. The union would form alliances between service providers and lived experience advocates to create purposeful and collaborative relationships that influence and improve outcomes for service users, service providers and policy makers. The function and structure of a lived experience union was sketched in the Victorian roundtable and is represented in Figure 4.

Figure 4: Lived experience union



Source: Author

Create and fund Lived Experience Commissioner roles

The strategy of creating and funding Lived Experience Commissioner roles is based on similar roles in other areas like mental health. (Examples can be found in the Mental Health and Wellbeing Commission 2023.) These paid leadership roles would have oversight, influence and authority in the housing and homelessness sectors. Issues of independence and authority in such roles need to be considered and addressed.

4.4 Policy and practice implications

Several policy and practice implications can be drawn from the findings of this project with many described previously. The key implications include the following:

- It is essential to recognise that housing and homelessness policy, service design and practice are in the early stages of embedding and operationalising lived experience participation and influence. This suggests there are many opportunities for federal, state and local governments and housing and homelessness organisations to build the conditions for world-leading approaches to lived experience participation in housing and homelessness policy, service design and practice. However, it is not possible to achieve this without investment in a range of areas, including paying PWLE for all activities at equitable and fair rates, and supporting the establishment and operations of an independent lived experience body—participants suggested a union—that would be a central source of expertise for the housing and homelessness sectors. Responsibility for this cannot rest solely with homelessness and housing organisations. It must be supported in policy and funding arrangements.

- Underpinning any discussion of lived experience participation and influence is the reality that many people are experiencing homelessness, at risk of homelessness or experiencing housing precarity. This means their basic needs and human right to safe and affordable housing must be met, as well as being able to access opportunities to participate and influence.
- Tinkering with homelessness and housing systems to add lived experience participation and influence is unlikely to create the cultural and paradigmatic change this report has identified is required. This indicates the need for a comprehensive lived experience strategy that is co-produced by and with PWLE at a national level, and which is then adapted to reflect unique jurisdictional contexts.
- The issue of structural violence requires immediate consideration and rectification by policy makers, funders and service providers. The drivers of this structural violence must be recognised—for example, underfunded services that are facing high demand from service users, while also attempting to bridge policy, funding and service delivery gaps or siloes. This recognition sits alongside the findings of this report that some services, policies and systems established to help people can harm them. These statements are not intended to blame, but rather to promote honest, open and accountable dialogue.
- Leadership in embedding lived experience participation and influence needs to occur in multiple contexts, such as federal and state governments, as well as research-funding bodies and higher education providers through their research and education activities.

4.5 Final remarks

[Lived experience participation and influence] leads to more efficient design [and] better identified priorities. It also leads to more effective system design because it helps identify things that someone without that lived experience may simply not have thought of in the first place. (PWLE)

This study highlights the wide array of benefits that lived experience participation and influence can offer. They include:

- improving policy relevance
- ensuring that services reflect actual need (thinking of the concept of desire paths)
- creating the conditions for empowerment
- undermining instances of structural violence.

These arguments reinforce the necessity of involving those directly impacted to ensure relevance, effectiveness and efficiency. Lived experience participation and influence is collaborative in nature, and while participants in this study highlighted experiences of structural violence and subsequent harm by services, policies and practitioners, they also expressed a strong desire for reciprocity and to work alongside and in partnership with policy makers, services and practitioners. This means bringing different perspectives together to respond to wicked and entrenched problems like homelessness and housing precarity. The motivation of PWLE needs to be recognised for its sense of responsibility to others who have similar experiences. This motivation, passion and commitment is a source of energy that could be directed purposefully.

Lived experience participation and influence is ultimately highly pragmatic, drawing on the lived experience and expertise of those who have lived with (or still are living with) a range of intersecting experiences and identities. It is fair to say that while there are many examples of good practice in the housing and homelessness areas, we continue to hear about service user experiences that are problematic and constitute forms of structural violence. This suggests that many current approaches are no longer fit for purpose, inviting a reconsideration and redrawing of policy, service and practice responses that place lived experience and expertise at the centre. Some of these solutions and responses will challenge existing ways of doing business, with multiple examples shared in this report—for example, the person whose solution to homelessness was tyres for their car rather than being placed in crisis accommodation.

Recognising the range of factors inhibiting lived experience participation and influence is a key first step. Barriers to lived experience participation and influence include:

- practitioner attitudes (Phillips and Kuyini 2017)
- difficulty sharing power with PWLE (Sandhu 2017)
- the time taken to work in participatory and inclusive ways, and limited experience of working with PWLE (Campbell, Campbell et al. 2021; Nelson and Zamora-Kapoor 2016)
- limited resources, accessible language and being the sole lived experience representative (Coleman, Byrd et al. 2017).

As Murinas (2017) notes, most of these factors relate to organisations and their readiness to embrace lived experience participation and influence. This suggests that attention needs to be paid to ensure policies, systems and structures are developed, implemented and monitored that enable lived experience participation and influence. While there are few guiding policy frameworks, standards and monitoring or auditing mechanisms to ensure lived experience participation and influence, it is unlikely that the work in this area will progress much further.

While this report has made several suggestions for the next practical steps, a key issue that requires attention is the power differential that appears to inhibit lived experience participation and influence. Such differentials have been framed as hierarchies of knowledge and expertise related to lived experience or formal qualifications. Such a cultural shift needs to occur in policy, funding, service delivery and practice actions. It means placing lived experience knowledge alongside professionally gained knowledge and qualifications, situating them as equal and relevant forms of knowledge, and resisting epistemic injustice. We finish with the words of a PWLE:

I think one of the biggest things that you'll never get in the textbook is how relentless homelessness can be, and that cumulative ... effect of day after day after day after day, especially some of the ways you have got to keep telling your story over and over and over to many people in the, you know, homeless support areas. (PWLE)

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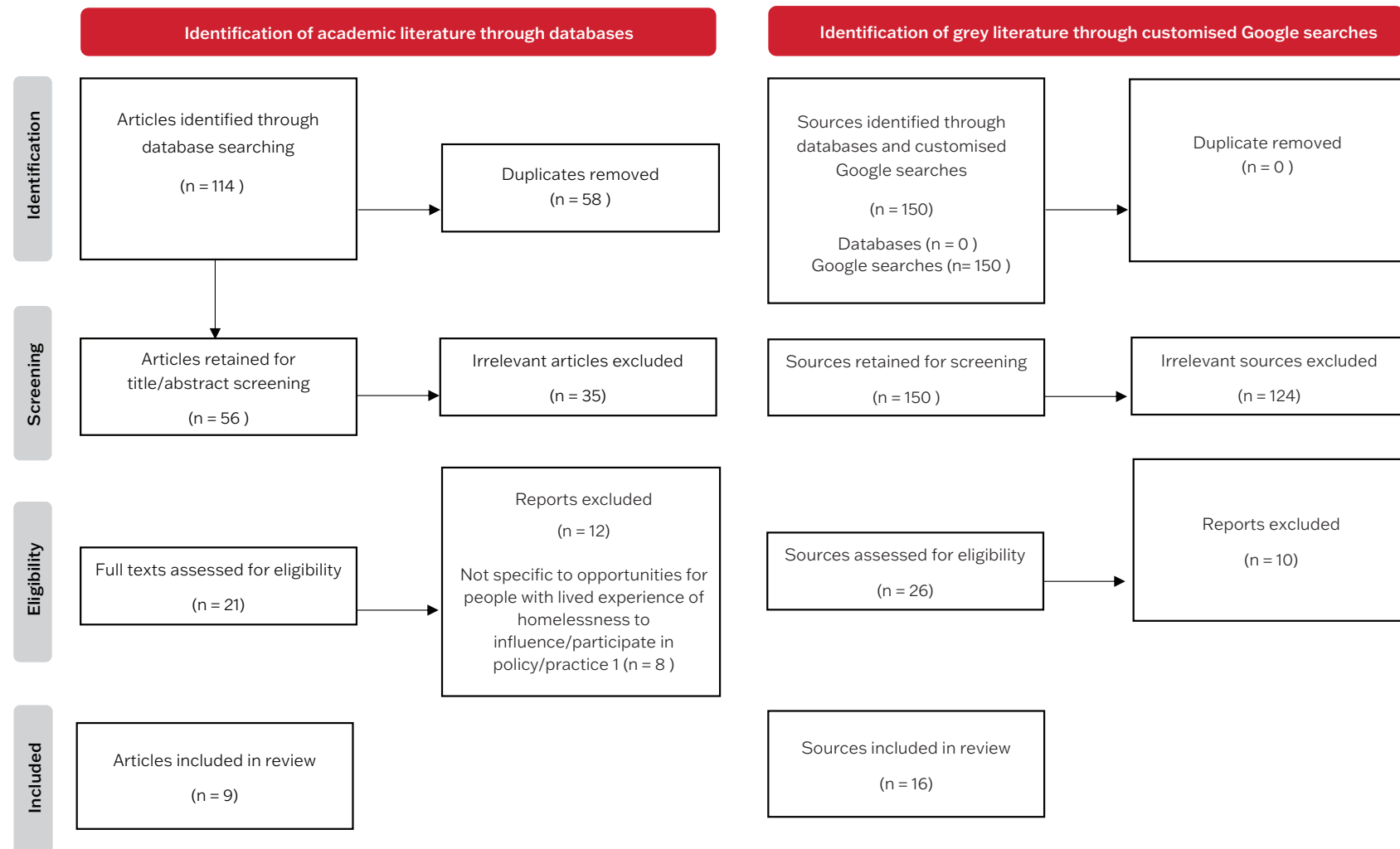
Appendix 1: Scoping review methods

Table A1: Scoping review search terms

Version 1	<p>Homeless* OR "crisis accommodation" OR "housing precarity" OR "crisis housing" OR unhoused OR unhomed OR houselessness OR unsheltered OR sheltered</p> <p>AND</p> <p>"lived experience" OR "lived experience perspectives" OR "service user expertise" OR "expert by experience" OR "consumer perspectives" OR "service user perspectives" OR "lived experience advisory group" OR "consumer advisory group"</p> <p>AND</p> <p>Collaboration OR "co-design" OR "co-production" OR "co-creation" OR "co-contribution" OR "consumer engagement" OR "consumer involvement" OR participat* OR co-participatory OR "parity of participation" OR "peer support" OR "peer workforce involvement" OR "self-advocacy" OR "service user engagement" OR "action research"</p> <p>AND</p> <p>policy OR practice OR "service delivery"</p>
Version 2	<p>Homeless OR "housing precarity" AND</p> <p>"Lived experience" OR "expertise by experience" OR "consumer perspective" OR "service user perspective"</p> <p>AND</p> <p>"Co-design" OR "co-production" OR "consumer engagement" OR "consumer involvement" OR participat* OR "peer support"</p> <p>AND</p> <p>Policy OR practice OR "service delivery"</p>
Amended version (For databases with restricted websites)	<p>homelessness</p> <p>AND</p> <p>"lived experience" OR "service user expertise" AND</p> <p>co-design OR "consumer involvement" AND</p> <p>policy</p>

Source: Authors

Appendix 2: PRISMA flow diagram



Appendix 3: Interview guide, focus groups

Nothing about us, without us: Focus-group questions

Preamble

- Welcome and thank people for taking the time to meet with us.
- Acknowledgement of Country.
- Facilitators introduce themselves.
- You are here today because we believe you have valuable contributions to make about how people who have experienced homelessness or housing problems can have a say and influence decisions about how services are delivered, policy and funding.
- We believe that your experiences and opinions are important and should influence decisions in housing and homelessness.
- If you have not already, please sign the consent form. (Note: we will need to ensure people have signed the consent form and understand the project = informed consent before the start of the focus group.)
- We are recording today's discussion so that we can type it up. This will help the research team to make sense of your views and perspectives.
- Please note you can choose not to answer any of our questions.
- You might like to take a break during the group and (research team member name) is here if you want to talk to someone.
- We will be taking a break for a cuppa and some food as well, but please help yourself in the meantime.
- Provide information on the toilets, exits and break-out spaces.

Questions

1. What do you think about people who have experienced homelessness or housing problems having input and influencing:
 - decisions affecting them.
 - the way services are delivered.
 - funding for services.
2. What difference does it make if people have input and influence?
3. What areas do you think people who have experienced homelessness or housing problems should have input and influence?

Prompts

Feedback on services received (also called client or consumer feedback or voice)	The type of services delivered	How services should be delivered
Funding of homelessness and housing organisations (type of funding, where the funding is directed, how much funding, how the funding should be accounted for)	Policies about homelessness or housing problems	Involvement in boards and other governance roles
Peer work	Advocacy	Education and awareness raising
What else?		

4. Have you had the experience of your input and influence making a difference in housing or homelessness services? (Prompt for examples.)
5. Have you had the experience of your input and influence being ignored, and if yes, why do you think this happened?
6. If you had service providers and decision makers (including maybe the Minister for Housing) in the room, what would you say to them about having input and influence?
7. Thinking about workers and managers in services, what could they do to ensure that people who have experienced homelessness or housing problems have input and influence? Prompt for:
 - attitudes
 - beliefs about competence and capability
 - practices (what could they do)?
8. Thinking about decision makers and funders (facilitators to give examples relevant to the context of the focus group, with some examples including Elders, government, peak bodies, sponsors, boards), what could they do to ensure that people who have experienced homelessness or housing problems have input and influence? Prompt for:
 - attitudes
 - beliefs about competence and capability
 - practices (what could they do)?
9. What do you think about people who have experienced homelessness or housing problems being employed in services?
 - What would/could this look like?
 - What are the challenges and opportunities?
10. Is there anything else you would like to say?

Thank you for talking with us today. Your input will make a difference to our understanding of these issues.

Appendix 4: Roundtable summary

Nothing about us, without us: Roundtable recommendations

Thank you for participating in the roundtable discussions. It was a rich discussion and has significantly contributed to the research team's understanding and our recommendations in the final report to the Australian Housing and Urban Research Institute (AHURI).

We will submit our report to AHURI on 1 May 2024 and it is under embargo for a few months. AHURI will send our report for review and feedback. Usually, this peer review is undertaken by academics, policy makers and service providers. We recognise the gap, in that people with lived experience do not contribute to the review process. We will respond to the review feedback and submit a revised version of the report to AHURI. It will take another few months before AHURI release the report. AHURI does not permit us to share the results of the research until the report is released, which we expect will be September 2024.

We are keen to have your ideas and feedback on the recommendations that we have collated below. Please share your feedback with Robyn using Track Changes or comments in an email by 14 April 2024.

We heard a range of suggestions and ideas at the roundtable, and have categorised your suggestions into:

- the **conditions** for lived experience influence and participation.
- the **principles** for lived experience influence and participation.
- the practical **strategies** to ensure lived experience influence and participation.

Conditions for lived experience influence and participation

1. Trauma-informed training and support is provided by and for people with lived experience and covers policy, practice and governance mechanisms, as well as topics relevant to the lived experience role. These training opportunities are supported by funded scholarships for people with lived experience.
2. The building of professional working relationships based on mutual respect, collaboration and recognition of lived expertise between people with and without lived experience is prioritised.
3. Communities of lived experience practice by and for people with lived experience are established.
4. Organisations are adequately resourced to build workforce capabilities (both lived experience and non-lived-experience staff) through policies, practices and professional development in order to enable genuine and meaningful lived experience participation and influence in all areas of core business, including decision-making.
5. Debriefing, reflection and decompression spaces are standard practice following any sharing of lived experience and expertise.
6. Clear communication is evident, including if lived experience roles change or are no longer required.

7. A minimum of two people with lived experience are appointed to positions, roles and tasks to ensure distribution of responsibility and a greater likelihood of different views and experiences informing decisions. The actual number of people with lived experience may increase, depending on context and focus.
8. Adequate, equal payment is required that recognises expertise, includes preparation time and does not expect people to volunteer.
9. Opportunities for lived experience involvement recognise that advocates are at different stages of developing their expertise and professionalism. This requires opportunities to develop as well as choose the level of influence and participation.
10. Lived experience discipline-specific supervision—that is, by and for people with lived expertise—is provided as a matter of course.

Principles for lived experience influence and participation

1. Recognise, develop and promote lived experience and expertise as its own discipline.
2. Promote systems reform—tinkering at the edges will not create the change required.
3. Recognise, respond to, and eliminate structural violence, which includes government and organisational responsibility to eliminate the systematic barriers that preclude people with lived experience exercising influence.
4. Recognise that lived experience qualifications and expertise are equal to any other form of qualification or expertise.
5. Create the conditions for people with lived experience to act and decide independently.
6. Ensure lived expertise is embedded from the beginning to the end of all cycles (including implementation and action).
7. Recognise that meaningful and purposeful lived experience employment and engagement promotes healing.
8. Develop lived experience frameworks and standards, building on and adapting existing lived experience frameworks, guidelines and strategies and adapt where appropriate.
9. Value and facilitate peer support between people with lived experience.
10. Create positions of leadership for people with lived experience in research, policy and practice, and ensure adequate and ongoing opportunities for the development of lived experience leadership capabilities.
11. Create a lived experience workforce that is safe, supported and supportive, has equal working conditions and facilitates retention.
12. Lived experience training, education and orientation for non-lived-experience workers is developed and delivered by people with lived experience.
13. Adopt transdisciplinary approach through bringing lived experience and other knowledges together.
14. People with lived experience identify and lead research to ensure usefulness and applicability.

Strategies to ensure lived experience influence and participation

Develop, implement and monitor transparent and accountable mechanisms in policy and practice that report on how user feedback is utilised and incorporated.

Lived Experience good practice standards

- To be co-designed through deep involvement and leadership of people with lived experience, with a focus on meaningful participation and influence.
- The standards are used to audit services and form the basis of training for people with and without lived experience to operationalise and enact.
- Audits of compliance with the standards are undertaken annually by a panel involving equal representation of people with lived experience, funders and other service providers (peers). Each stakeholder (including PWLEs) has equal and independent decision-making authority and influence.
- Funding penalties are applied if the standards are not met (and after the organisation has time to rectify the identified issues).

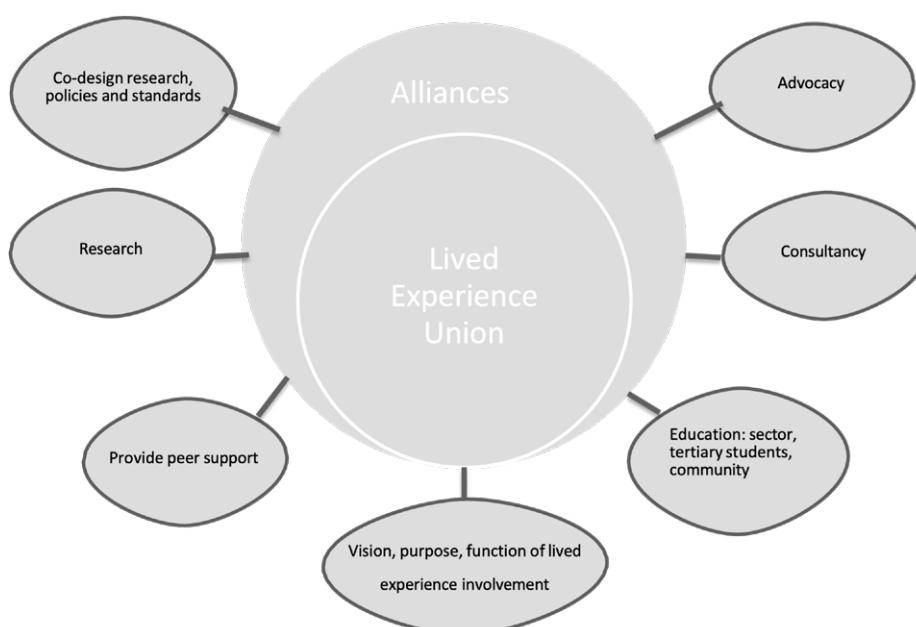
Lived Experience panels

These panels work collaboratively with service providers to assist in problem solving within practice. Lived experience panel members would have equal and independent decision-making authority, and be subject to the same expectations regarding confidentiality and professional behaviours. For example: *Behaviour of residents in shared residential facilities (such as rooming houses) and instead of staff deciding what needs to happen (which often creates further harm or risk for other residents), the Lived Experience Panel would work collaboratively with the staff to identify solutions and responses.* (PWLE)

Lived Experience commissioners

- These roles would have oversight, influence and provide leadership in the lived experience and homelessness and housing sectors.
- Paid roles required, modelled on mental health lived experience commissioner roles in other jurisdictions.

A lived experience union (all forms of lived experience)



This union would be funded to act as an independent body and its structure (i.e. for profit, not-for profit, etc) would be decided upon establishment of the union. Roles include:

- advocacy to government, industry and other stakeholders—including the detrimental impacts of current funding models in human services sector and promoting person-centric rather than service-centric approaches
- developing standards and good practice guidelines
- consultancy
- education and research (design and delivery)
- build alliances with other lived experience communities and organisations
- develop vision, purpose and function for lived experience involvement in housing and homelessness policy, practice, research and education.



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