

Lived Experience Literature and Practice Review

Approaches to embed the voice of refugee lived experience
in decision-making

October 2023

Contents

| | |
|---|----|
| Introduction | 2 |
| Context: The Current State of Lived Experience Scholarship and Practice. | 2 |
| Guiding Principles | 4 |
| Meaningful..... | 4 |
| Accountability | 5 |
| Valued | 5 |
| Inclusion | 5 |
| Self-Representation..... | 6 |
| Partnership..... | 6 |
| Safety | 6 |
| Methods..... | 7 |
| Inform..... | 8 |
| Consult..... | 8 |
| Involve..... | 8 |
| Collaborate..... | 8 |
| Empower | 8 |
| Enablers | 9 |
| References | 11 |
| Practice Examples..... | 11 |
| Research, Reports and Guidance..... | 11 |

Introduction

The purpose of this review is to provide an overview of the evidence and practice on engaging refugee lived experience in decision-making. The review will inform the design of a framework for engaging lived experience in the implementation and evaluation of the NSW Settlement Strategy (managed by Multicultural NSW) and the development of guidelines to support the NSW Government to engage refugee lived experience in decision-making more broadly.

The review was guided by three high-level questions:

- What are the benefits of engaging lived experience?
- What principles should guide effective engagement of lived experience?
- What are the most effective methods to engage lived experience?

To answer these questions, the review focused on evidence specific to engaging refugee lived experience, but also included relevant evidence on engaging other types of lived experience. The review also sought to identify practice examples of lived experience frameworks and other mechanisms to operationalise processes for lived experience engagement. The review focused on systematically mapping lived experience practice that already exists in the NSW Government, but also considered other public and community sector practice examples.

An overarching learning from the review is that most of the evidence and practice related to refugee lived experience is at the international level, in the context of refugee participation in global refugee policy and international humanitarian responses. There is more limited evidence specific to settlement contexts and participation of refugees in local and national decision-making. There is, however, a significant body of evidence and practice related to engaging other types of lived experience at the national and local level, in particular disability, mental health, and First Nations.

Context: The Current State of Lived Experience Scholarship and Practice

Lived experience, or expertise by experience, is increasingly utilised in the design, implementation, and evaluation of policies, programs, and services (Smith-Merry 2020). Nevertheless, there is a lack of international and national *best practice* on engaging lived experience (Feige and Choubak 2019). It is an evolving area of practice.

Regarding refugee lived experience specifically, there has been a growing focus on greater participation of refugees in decisions that affect them (Harley and Hobbs 2020). Milner observes that “[a] prominent theme of UN agreements on refugees since 2016 has been a commitment to enhancing the role of refugees in the making and implementation of policies that affect them” (Milner 2021). Most notably, paragraph 34 of the UN’s 2018 Global Compact on Refugees (GCR) states:

Responses are most effective when they actively and meaningfully engage those they are intended to protect and assist. Relevant actors will, wherever possible, continue to develop and support consultative processes that enable refugees and host community members to assist in designing appropriate, accessible and inclusive responses. States and relevant stakeholders will explore how best to include refugees and members of host communities, particularly women, youth, and persons with disabilities, in key forums and processes, as well as diaspora, where relevant.

While there is limited literature on refugee participation (Milner 2021), in recent years there have been attempts to define meaningful refugee participation (Harley 2022) and to develop guidance on approaches in practice. Notably, in 2020 the Global Refugee-led Network and Asylum Access drafted guidance for stakeholders to ensure refugee participation is meaningful. There is no one standard definition of what constitutes meaningful refugee participation (and there is debate in the literature as to whether this is needed), but the guidance developed by the Global Refugee-led Network and Asylum Access offers the following definition:

When refugees – regardless of location, legal recognition, gender, identity and demographics – are prepared for and participating in fora and processes where strategies are being developed and/or decisions are being made (including at local, national, regional, and global levels, and especially when they facilitate interactions with host states, donors, or other influential bodies), in a manner that is ethical, sustained, safe, and supported financially (GRN and Asylum Access 2020)

Milner argues that in global policy contexts, refugee participation is a policy norm that either exists or is actively emerging, and the focus is now on moving from ‘if’ to ‘how’ (Milner, 2021). There is evidence of this norm in Australia’s engagement in global refugee policy. Australia was one of four states to sign a refugee participation pledge during the Global Refugee Forum in December 2019, and in September 2023 the Commonwealth Government announced plans to create an Australian Refugee Advisory Panel. The Refugee Advisory Panel will be a formal mechanism to enhance meaningful refugee participation in Australia’s engagement with the international refugee protection system and humanitarian assistance.¹

There is less evidence for an established policy norm for refugee participation at the national and state level, although there is an emerging norm of engaging lived experience more generally in public policy. Looking at the NSW Government specifically, the review identified eighteen publicly available formal mechanisms related to lived experience (or experiential expertise) in decision-making. There is potential to draw on this existing practice to develop specific mechanisms for engaging refugee lived experience in the NSW Settlement Strategy and wider NSW Government decision-making.

Table 1. Existing NSW Government lived experience practice

| Portfolio | Department / Agency | Mechanism | Experience |
|----------------------|-----------------------------|---|---------------|
| Premier’s Department | Aboriginal Affairs NSW | OCHRE: NSW Government Plan for Aboriginal Affairs | First Nations |
| | | Local Decision Making: Policy and Operational Framework | First Nations |
| Education | NSW Department of Education | Student Voice Framework | Students |
| | | NSW Aboriginal Education Consultative Group | First Nations |

¹ <https://www.homeaffairs.gov.au/news-media/archive/article?itemId=1118>

| Portfolio | Department / Agency | Mechanism | Experience |
|-------------------------|---|---|--|
| Health | NSW Ministry of Health | All of Us: A guide to engaging consumers, carers and communities across NSW Health | Healthcare consumers and carers |
| | | Elevating the Human Experience: Our guide to action for patient, family, carer, volunteer and caregiver experiences | Patients and their families and carers |
| | | Framework for Mental Health Lived Experience (Peer) Work in South Eastern NSW | Mental health |
| | Mental Health Commission of NSW | Lived Experience Framework for NSW | Mental health |
| | NSW Agency for Clinical Innovation | Working With Consumers guidance | Healthcare consumers |
| | | Co-Design Toolkit | Healthcare consumers |
| Transport | Transport for NSW | Aboriginal Participation Strategy | First Nations |
| | | Principles and Framework for Aboriginal Engagement | First Nations |
| Customer Service | NSW Department of Customer Service | Aboriginal Customer Engagement Strategy | First Nations |
| | State Insurance Regulatory Authority | Engaging with Lived Experience Framework: A strategic framework for guiding our work impacting mental health | Mental health |
| Communities and Justice | Aboriginal Housing Office | Aboriginal Reference Group | First Nations |
| | | AHO Engagement Framework | First Nations |
| | NSW Police Force | Framework for Community Engagement | N/A (community wide) |
| | Office for the Advocate for Children and Young People | Engaging children and young people in your organisation | Children and Young People |

Guiding Principles

One of the key elements, or purposes, of lived experience frameworks is to define overarching principles that guide engagements. While these principles vary depending on the type of experience, some common themes were identified in the review.

Meaningful

The majority of practice examples reviewed made some reference to meaningful engagement as an essential principle. In practice, this principle guides engagements to be **authentic**. It distinguishes meaningful engagements from engagements that are tokenistic or 'tick the box exercises' and do not inform or have **influence on decisions**.

Meaningful engagement is also associated with the level of **collaboration**; specifically, moving beyond storytelling and passive consultation to also include opportunities for people with lived experience to actively participate in, or lead, certain decision processes or initiatives. Milner found “[o]ne of the greatest concerns expressed by refugees participating in global policy processes is that they will be asked to “tell their story” at the outset, be excluded from the substantive discussions, but for their presence to subsequently be highlighted as a way of legitimising the process itself.” (Milner, 2021)

Accountability

Engagements of lived experience should lead to **action**, and when concerns are raised these should be addressed and responded to; “[...] many people with refugee lived experience have spoken about the need to move beyond being given opportunities to give voice to their personal experiences (‘telling stories’), and towards being given space to both speak and exert influence in decision-making fora.” (RCOA 2017)

It requires a **commitment** to engage lived experience and to listen to it, not just when it is convenient to do so, or when it aligns with the status quo and validates existing views.

This principle is also expressed as ensuring engagements are done in ways that are **purposeful** and **transparent**. There should be a clear rationale for why lived experience is being engaged, transparency about how insights will be used, as well as honesty about what decisions can’t, or won’t, be influenced. On a practical level, this requires that people with lived experience are kept **informed**; the need to close the feedback loop and ensure that people are updated on how their inputs were actioned (or if not, why not) was a common recommendation.

Valued

Lived experience should be valued as a type of **expertise**. In one practice example, lived experience was described as context expertise that is distinct from, but has equal value to, content expertise i.e. insights from subject matter experts and practitioners (Mission Australia 2020). Both types of expertise are valuable, but one without the other provides only a partial understanding of the issue. This principle requires a departure from traditional thinking about evidence-based policy that links the validity of knowledge to the training (usually academic qualifications) that sits behind it (Smith-Merry 2020).

Inherent in this principle is also the concept of **respect** for and **recognition** of both the contributions that people with lived experience make and the validity of their insights. Insights provided by experts by experience have traditionally been provided in volunteer, unpaid and/or unreimbursed capacities, and often given less weight. Similarly, the contributions of people with lived experience are often not formally acknowledged or acknowledgments are very general (e.g. vague references to “people with lived experience were consulted”) that don’t recognise specific individuals or organisations who made substantive contributions.

Inclusion

Refugee experience is **diverse** and engagements need to account for this (in terms of the types of participation, issues addressed, and how lived experience is understood). Linked to this, the need to **contextualise** engagements was highlighted in a number of the resources reviewed. “Refugee voices and means of meaningful participation will be different depending on context” (uOttawa and LERRN 2019)

Similarly, it was noted that refugee experience is only one aspect of a person's identity, among others. **Intersectionality** needs to be considered in engagements to understand other characteristics of a person's identity - such as gender, sex, sexual orientation, nationality, religion - and how these may create or exacerbate barriers to participation, increase marginalisation, or inform people's experiences (Harley and Wazefadost 2022). "Care should be taken to ensure this participation is broad and includes perspectives that can often be marginalized, such as those of women, girls, and other minorities." (Refugee Hub and LERRN 2019)

Given the need to account for diversity, a key learning is that engagements should be as inclusive as possible (appropriate to the issue) and doing so requires **accessibility** and **flexibility**, in terms of adjusting approaches and operating in different ways. It also requires inclusive approaches to how lived experience is recruited; for example, the "[...] importance of avoiding a privileging of "favored refugees" – those refugees who conform to the image of the refugee that aligns with the preferences and interests of dominant actors within the refugee regime." (Milner, 2021) Linked to this, there is some discussion in the literature and practice about the challenges of **representation** and which individuals and organisations can legitimately claim to represent the views of a diverse group like people with refugee lived experience. Advice on this issue is pragmatic; representation challenges should not be used as an excuse to not engage lived experience, imperfect representation is better than no representation (uOttawa Refugee Hub and LERRN).

Self-Representation

Refugees should have – and policy-makers and other stakeholders should recognise – the meaningful **agency** of refugees to make decisions that affect their lives (Feige and Choubak 2019). "Refugee communities usually hear about other people advocating about them. We decided that was not good enough. We want to be actually engaged, not just the voices, we want our voices heard but we also want to sit down and do self-representation" (Atem Atem quoted in RCOA 2017). This requires stakeholders (NGOs, government and others) to "[...] make space for refugee inputs, relinquishing decision-making power whenever/wherever possible" (RCOA 2017) and may involve refugees creating their own networks and forums for consultation that are self-directed/managed.

Partnership

Engagements of lived experience should be **sustained** and **ongoing**. The aim should be to build enduring, strategic relationships, as opposed to one off and transactional engagements. In part, this principle is about building **mutual trust** to ensure that decision makers and people with lived experience have motivation, capacity and opportunities to work together.

It also involves prioritising **support** to people with lived experience to enable them to participate in policy processes as equal partners. In turn, equality in partnership requires **power sharing** and awareness of, and actions to address, underlying power imbalances and biases.

Safety

Some of the common characteristics of refugee lived experience - notably uncertain legal status, experiences of trauma, mistrust of government and other authorities, stigma and social isolation – necessitate that engagements be guided by consideration and mitigation of

protection risks. Any engagement should be done in trauma informed ways, manage privacy risks, and create cultural safety.

Methods

A key learning of the review is that the methods and approaches to engage lived experience should be appropriate to the goals of the engagement, and linked to this, the level of participation in the decision by those being engaged.


There is no one way to do this, but the IAP2 spectrum of public participation is used widely in the practice examples and research considered in this review. It is used as a way of organising and selecting the most appropriate methods, for the level of participation the engagement is aiming for. All levels of participation are legitimate as determined by the goal of the engagement.

In addition to specific methods to engage lived experience, the literature and practice examples reviewed included recommendations for cross-cutting enablers that support engagements at all levels and build the capacity of organisations and decision-makers to engage with lived experience in effective ways.

As noted earlier, lived experience engagement is a developing area of practice. While the review found a rich discussion on methods and approaches, no research was identified that evaluated the effectiveness of these methods. This could be a priority for future research.

Table 2 below summarises the various methods that were referenced in the literature and practice examples.

Table 2. Methods to engage lived experience²

| Increasing level of participation in and influence over the decision | | | | |
|--|---|---|--|--|
|  | | | | |
| Inform | Consult | Involve | Collaborate | Empower |
| Provide information to people with lived experience (about issues and decisions-made) | Obtain feedback from people with lived experience (generally or on specific decisions) | Work together with people with lived experience in decision-making | Partner with people with lived experience in each aspect of a decision | Devolve certain decision-making to people with lived experience |
| <ul style="list-style-type: none"> • Factsheets and brochures • Newsletters • Social media • Helpline • Community education and awareness campaigns (including opportunities to provide inputs) • Information sessions • Human-centred communications that are aligned to 'moments that matter' • Localised / targeted communication • Briefings on funding opportunities / | <ul style="list-style-type: none"> • Surveys and pulse checks (experience, satisfaction, engagement, feedback etc.) • Targeted focus groups and experience groups • Consultation meetings (invite-only or public) • Public hearings • Town hall meetings / open-mic events • Policy dialogues • Opinion polling • Feedback and complaints mechanisms for PwLE • Suggestion box | <ul style="list-style-type: none"> • Committees and working groups • Workshops and roundtable discussions • Advisory groups (e.g. Advisory Councils or Panels or reference groups) • Empathy Maps, Life Journey Maps and 'personas' • Social procurement (including consultants) • Orientations ahead of working together • Client-reported outcome and experience measures included in M&E / reporting frameworks | <ul style="list-style-type: none"> • Co-design or co-production (of policies, programs, services) • Co-leadership / delivery of implementation and evaluation, for example: <ul style="list-style-type: none"> ○ Project sponsorship ○ PwLE Steering Committee ○ Shared evaluation systems / measurement processes • 'Collaborative Pairs' programs • Formal partnerships with PwLE organisations/networks (e.g. MoUs) | <ul style="list-style-type: none"> • PwLE-led or operated programs / services / research • Decision-making bodies • Recruitment of PwLE into leadership roles • PwLE-set KPIs • Participation in new funding opportunities • Support/capacity sharing for self-representation: <ul style="list-style-type: none"> ○ Leadership ○ Advocacy ○ Policy / decision-making processes (e.g. support to prepare inquiry submissions) |

² IAP2 Spectrum of Public Participation 2018 – used with permission

| | | | | |
|--|--|--|---|---|
| <p>advertisements in lived experience communities</p> <ul style="list-style-type: none"> • Parliament visits • Communications / updates on how inputs have been used | <ul style="list-style-type: none"> • Story telling / personal narratives <ul style="list-style-type: none"> ○ Repository of stories ○ Case studies | <ul style="list-style-type: none"> • Outcomes Summit • Consensus conferences • Citizen juries / panels • Planning cells • Consultative groups | <ul style="list-style-type: none"> • Recruitment and retention of PwLE into paid or voluntary roles: <ul style="list-style-type: none"> ○ Designated roles ○ Non-designated roles ○ Peer Workers and advocates ○ PwLE advisors / reps ○ Diversity recruitment and leadership equity initiatives ○ PwLE cadet/intern programs ○ Measurement of experiences / perceptions of PwLE in the workplace • PwLE involvement in recruitment processes and panels • PwLE representation in governance (e.g. Board members) | <ul style="list-style-type: none"> ○ Organisational development (including fundraising and grant management) ○ Mentoring • Access to trainings and other development opportunities |
| Enablers | | | | |
| <ul style="list-style-type: none"> • Compensation and/or reimbursement for substantive contributions (both financial and in-kind) • Capacity building: <ul style="list-style-type: none"> ○ Training on the value of lived experience ○ Training on how to manage engagements | | | | |

- Training for managers of PwLE
 - Cultural capability training
 - Cross-gov CoP to share data, ideas, experiences related to engaging lived experience
- Dedicated and sustained resourcing (financial and non-financial)
- Institutionalising engagement of lived experience and embedding in business as usual through policies and formal frameworks
 - Engagement standards
 - Engagement guidelines
 - Paid Participation policies
 - Safeguarding policies
 - Grievance policies
 - Position Descriptions that include engagement of lived experience as standard
 - Audits of policies, procedures, guidelines to identify gaps
- Shared / centralised government evidence base (PwLE expectations, experiences, behaviours, outcomes)
- Trauma-informed policy and care
- Cultural competency
- Informed consent models
- Accessible language (translation and interpretation, plain language that avoids sector jargon)
- Accessible, safe, and welcoming spaces

References

Practice Examples

- Family Safety Victoria (2022) *Family Violence Lived Experience Strategy*
- Kaldor Centre (2023) *Guidelines for Co-Produced Research with Refugees and Other People with Lived Experience of Displacement*
- Mind Australia (2021) *Mind's Lived Experience Strategy 2021-2024*
- Mission Australia (2020) *Learning from Lived Experience: A Framework for Client Participation*
- NSW Agency for Clinical Innovation, *Working with Consumers*
- NSW Department of Customer Service, *Aboriginal Customer Engagement Strategy 2021-2025*
- NSW Government (2021) *The NSW Customer Strategy: Towards a customer-centric government*
- NSW Health (2021) *Elevating the Human Experience: Our guide to action for patient, family, carer, volunteer and caregiver experiences*
- NSW Health (2022) *All of Us: A guide to engaging consumers, carers and communities*
- NSW Mental Health Commission (2018) *Lived Experience Framework*
- NSW Police Force (2020) *Framework for Community Engagement*
- NSW State Insurance Regulatory Authority (2020) *Engaging With Lived Experience Framework*
- Safe + Equal (2020) *The Family Violence Experts by Experience Research Report and Framework*
- Transport for NSW, *Principles and Framework for Aboriginal Engagement*
- Victoria Department of Health and Human Services (2019) *Client Voice Framework for Community Services*
- WHO (2023) *Framework for Meaningful Engagement of People Living with NCDs and Mental Health and Neurological Conditions*
- World Wellness Group, *Multicultural Lived Experience Framework*

Research, Reports and Guidance

- Atem Atem (2017) Wellbeing from the Refugee Lived Experience Perspective Presentation at 'From Surviving to Thriving: Refugee Journeys' conference, South West Sydney Wellbeing Collaboration
- Bevan Foundation (2020) *Embedding Lived Experience in Migration Policy Debates in Wales*
- CFE Research (2020) *The Role of Lived Experience in Creating Systems Change*

Feige, S & Choubak, M (2019) *Compensating people with lived experience: best practices from the literature*

Global Fund to End Modern Slavery and National Survivor Network (2023) *Meaningful Engagement of People with Lived Experience*

Global Refugee-Led Network and Asylum Access (2019) *Meaningful Refugee Participation as Transformative Leadership: Guidelines for Concrete Action*

Harley T (2022) Hobbs H (2020) The Meaningful Participation of Refugees in Decision-Making Processes: Questions of Law and Policy, *International Journal of Refugee Law*, 32.2

Harley T (2022) Beyond Storytelling: Refugee Participation in Decision-Making Processes

Harley T, Lee S and Wazefadost N (2022) *Not just a seat at the table: Refugee participation and the importance of listening* *Forced Migration Review* issue 70

Homer, A (2019) *10 Engaging People with Lived/Living Experience: A Guide for Including People in Poverty Reduction*

IAP2, (2018) *Spectrum of Public Participation*

Milner J (2021) *The Politics and Practice of Refugee Participation in the Governance of the Global Refugee Regime* Paper presented to Canadian Political Science Association Annual Conference 'Diversity and the Discipline of Political Science'

Pathway Healthcare for Homeless People (2020) *Best Practice Guidance - Lived Experience*

uOttawa Refugee Hub and LERRN (2019) *Outcomes Document: The Role of Refugees in Response to Displacement, How Can Canada Support and Facilitate Refugee Participation in Local, National and Global Settings?*

RCOA (2023) Working Ethically and Responsibly with Refugees and People Seeking Asylum

RCOA (2017) *Nothing About Us Without Us: Getting serious about refugee self-representation* Report on 2017 UNHCR Annual Consultations with NGOs side event

RCOA (2017) *Wellbeing from the Refugee Lived Experience Perspective*

Refugee Action Good Practice, *Experts by Experience Guidance*

Smith-Merry, J (2020) *Evidence-based policy, knowledge from experiences and validity*

STARTTS (2022) *Working with People from Refugee Backgrounds: A Guide for Social Workers*

Sydney Policy Lab, The University of Sydney (2022) *'No Data Without Us': Community responses to the idea of a National Disability Data Asset*

US Department of Health and Human Service (2021) *Lived Experience Brief*