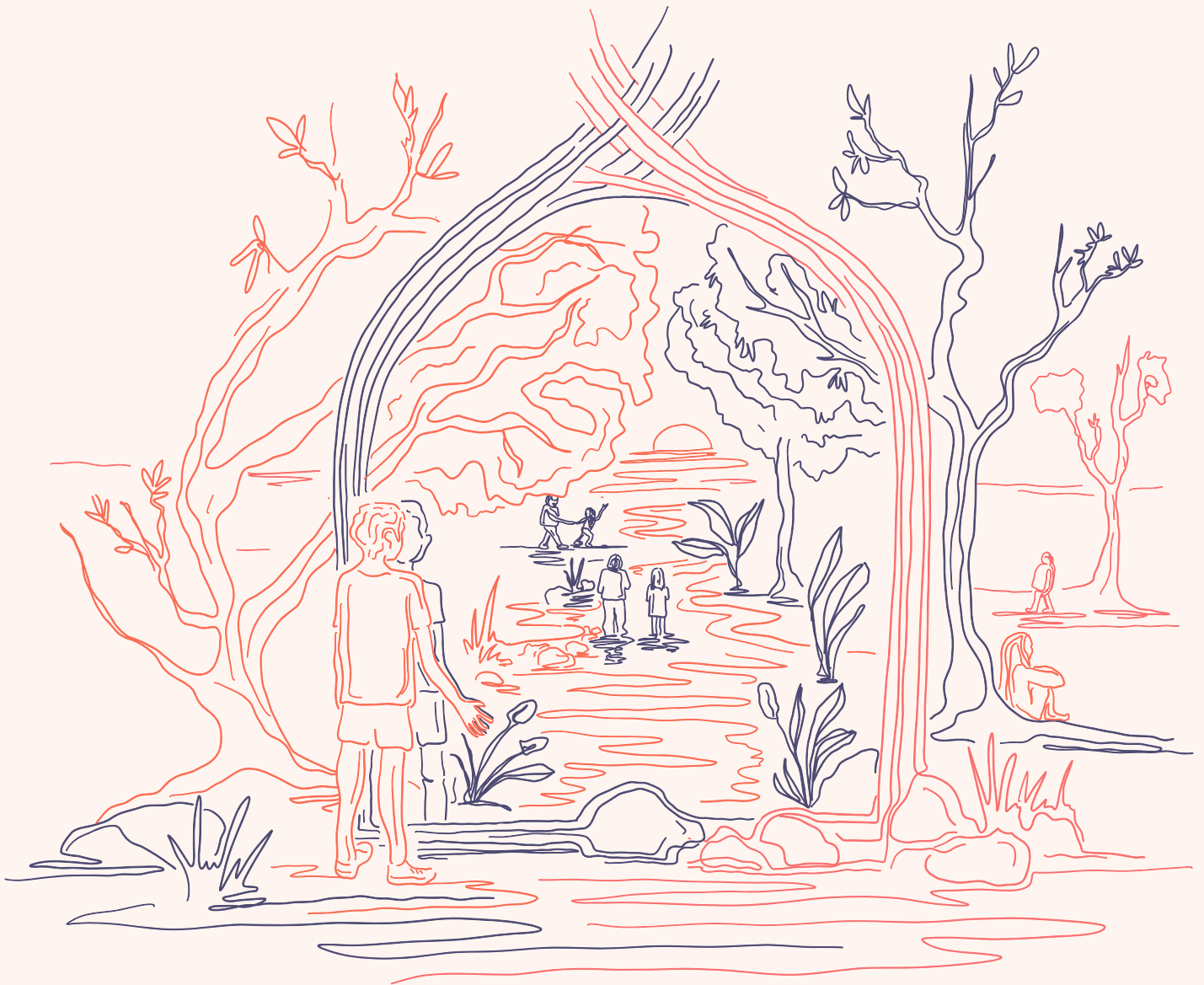


PROJECT UPDATE 1

# On Our Own Terms

Developing lived experience advocacy and leadership for social sector systems change



‘Ethical representation of survivors... needs a systemic shift. This is an agenda that welcomes allies. But in order to get there, our allies must proactively share power, deconstruct and withdraw their investment in the status quo, and engage in the creative process of community building... Allies must also be willing to shield people with lived experience from constantly justifying their worth and elevate people with lived experience at all opportunities.

We invite you to ask and act strategic, systems-shifting questions. Instead of “What does ideal representation look like?,” let’s ask “What does a movement led by survivors look like?” No longer is it “nothing about us without us.” It is time for social movements to be by us and for us.’

– Minh Dang, “The Paradox of Survivor Leadership,” in *Wicked Problems: The Ethics of Action for Peace, Rights, and Justice* (2022).

## Credits

### Project team

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# About the project

*On Our Own Terms* explores the contours of lived experience advocacy and leadership across a range of contexts in the Australian social sector. The project is convened and conceptualised by people with a breadth and depth of lived and living experience and expertise.

## About this update

This first project update provides an overview of the project, including objectives, principles and emerging knowledge and insights from our initial engagement with the literature.

This provides important grounding for the work we are doing in our next phase, which involves deep conversation with a range of leaders across Australia who work to challenge and change systems that harm and hold inequalities in place.

# Emerging insights at a glance

Here's a snapshot of the key themes and insights that have emerged from our initial engagement with the literature as part of the first phase of the project.



## Power and leadership

**Key insight:** Lived experience leaders work with and transform their own power and power within systems in order to bring about positive change for their communities.



## Producing and legitimating knowledge

**Key insight:** Recognising and integrating lived experience leadership outside academic confines is key to expanding the existing knowledge base.



## Palatability politics

**Key insight:** Systems have limited capacity for embracing difference and views which are considered 'radical' are not always welcomed.



## Contexts of enactment

**Key insight:** Lived experience leadership exists inside, outside and beyond institutions.



## Equity and justice

**Key insight:** Compounded oppression and marginalisation constrain lived experience leadership, often leading to the centring of those with existing power and privilege.



## Tokenism without supportive structures

**Key insight:** Meaningful lived experience leadership requires practices and systems that are fit for purpose.



## Staying true

**Key insight:** Some lived experience leadership contexts make it difficult to stay true to activist roots.



## Merit over mechanics

**Key insight:** Understanding the structural mechanics of lived experience leadership is essential for thriving cultures.



## Embodied leadership, positional authority and continuum thinking

**Key insight:** Lived experience leadership continues to be cast in terms of continuum or hierarchical thinking, with formal 'leadership' considered the 'peak' of participation.



## Professional development for lived experience leaders

**Key insight:** Tailored training for lived experience leaders and non-lived experience leaders, designed by lived experience leaders themselves, is key.

# Project intention

There is a groundswell of activity across Australia to increase the involvement of people with lived experience in social sector change, particularly those with experiences of historical and contemporary exclusion and marginalisation. This project builds from the deep, historical, and foundational advocacy, activism and vision of justice and liberation focused movements.

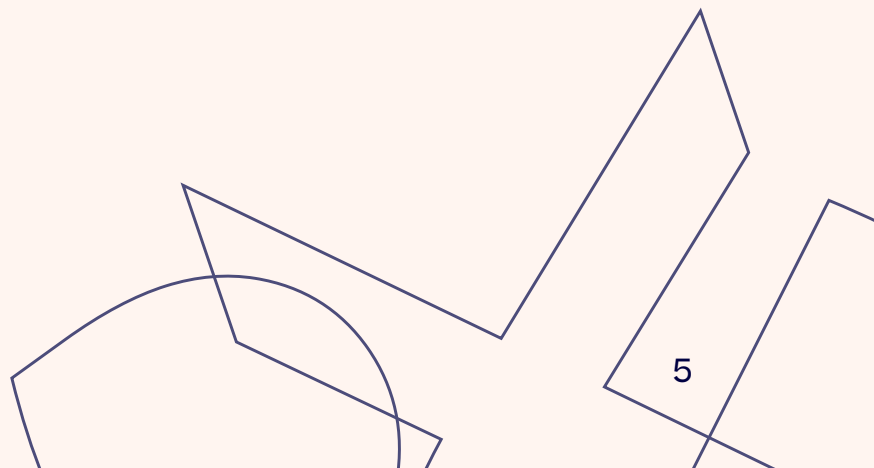
While we are excited to see new initiatives that seek to create space and conditions for different kinds of leadership, we're also aware that much of the current focus, framing and understanding of lived experience leadership and ways of engaging are within an institutional context. We want to take this opportunity to pause and reflect on the politics of lived experience leadership for community and system leaders outside of predominantly institutional framing.

*On Our Own Terms* is not only interested in supporting existing institutions get better at engaging with people with lived experience, it is also interested in radical new propositions that people with lived experience bring to social change, and forms of leadership that are not currently in view. We want to learn from and with these people and spotlight the different forms of leadership that are changing systems across Australia – not just from within institutions but outside of, and often, despite them.

**Lived experience leadership is often discussed as if it is 'new', not something deep and historical which has always been an integral part of how change happens. Part of our aim is to reflect on expanded definitions and understanding of lived experience leadership that recognises:**

- Leadership not just seen in spaces that institutions create and invite people into, but also in spaces *beyond* institutions that people lead in and create change from
- The leadership and influence that these people generate through the quality and integrity of their ideas, actions, and ability to build movements around cases for change.

As well as new roles that are being established within existing systems which have considerable institutional power, change also happens through the actions of leaders who decide *not* to participate or partake in dominant systems as they are now, and instead push us towards new possibilities.



# Project principles

We recognise that research projects such as this one can be extractive and harmful to people and communities. So, we are striving to create different conditions as part of *On Our Own Terms*.

This project seeks to gather, collate, synthesise and interrogate some of the different strands of knowing, being and doing in lived experience advocacy and leadership for systems change. Much of what we've drawn from is inspired by collective movements, in addition to specific sources.

**Of those published or publicly available to us as part of the project engagement with the literature**, we have drawn from a range of foundational, contemporary and broad scholarship on lived experience leadership. Some of these authors are referenced in this update. We do not claim to have undertaken a systemic review of all materials and recognise that there will be community leaders whose work is not published, well known, or available to us.

This project would not be possible without the work that has come before; we are aware that we stand on the shoulders of giants, those working within systems and writing academically, and those working outside and in-between systems, whose views we seek to engage with and foreground.

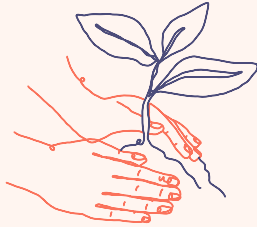
We are also drawing from our own insights, generated through the project process, conversations with each other, and our own personal and practice experiences with and around lived experience leadership. Of course, we are limited by our own positionality, however – our own sensemaking as a group has been a critical and valuable source of knowledge in and of itself. A constant focus of attention for us is *reflexivity*, the capacity to invite critique and question our own biases and assumptions.

**With this in mind, the following principles help guide and keep us accountable to the integrity of this work, and as something much bigger than us as the project team.**



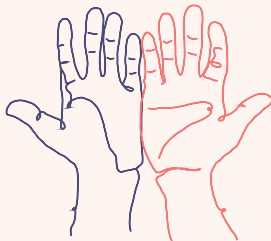
## Relationships first

- We lead with and through relationships
- We consider humans before research
- We take care of people before we take care of 'data'



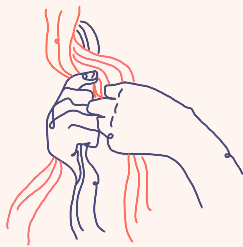
## Emergence

- We build conditions which are conducive for collective knowledge to form
- We hold complexity and facilitate for emergence
- We commit to following the path where it takes us, with no strict stance about what 'great' lived experience leadership looks like and where it might come from



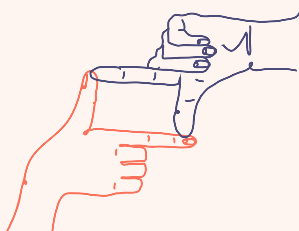
## Open stance

- We approach all aspects of this project with curiosity and openness
- We show up with intention, generosity and humility
- We work in ways that are reciprocal and generative
- We commit to being as honest and upfront as possible at all times



## Epistemic justice

- We value people's own ways of knowing
- We use non-extractive and participatory research methods which seek to create and capture collective wisdom that everyone benefits from
- We iterate and build community along the way and this community shares in the knowledge
- Everyone who is involved is supported to contribute in ways that work best for them



## Reflexivity

- We continuously reflect on our positions and identities and are both thoughtful and critical about how these influence how we see, understand and make sense of things
- To counter this, we seek the feedback of a wider network who will challenge and reveal mindsets and attitudes that could be acting as constraints

# What knowledge is emerging?

A brief, preliminary and broad engagement with the literature on lived experience leadership reveals an emerging body of knowledge, concentrated in and around mental health contexts.

While lived experience engagement and participation has proliferated, with frameworks and best practice models springing up in service design and delivery, and policy and research contexts, the emphasis remains on inclusion, partnership, co-design, co-production and the incorporation of a lived experience lens *within* mainstream systems.

This does not reflect the explosion of lived experience *led* initiatives and justice-based advocacy for social transformation. From First Nations leadership through to increasingly community-led and informed service design, delivery and research, there is no shortage of examples of lived experience leadership in action. Several key pieces of work recognise and underscore the role lived experience leadership has for systems transformation.<sup>1,2,3,4,5,6,7</sup> Social and communal purpose is central to lived experience leadership and there is broad understanding that this work cannot be undertaken in isolation.

Lived experience leadership takes place within institutions, in proximity to and through shared power with mainstream leaders, and it also takes place independently of these contexts.<sup>8</sup>

## Definitions and domains

**Some of the terms describing the practice include:**

- Lived experience leadership<sup>9,10,11,12,13,14</sup>
- Patient leadership<sup>15</sup>
- Mad leadership<sup>16</sup>
- User/survivor leadership<sup>17</sup>
- Survivor leadership<sup>18</sup>
- Consumer leadership.<sup>19</sup>

Services, actions and work that are peer led,<sup>20</sup> or community-led,<sup>21</sup> can also be understood as lived experience leadership.

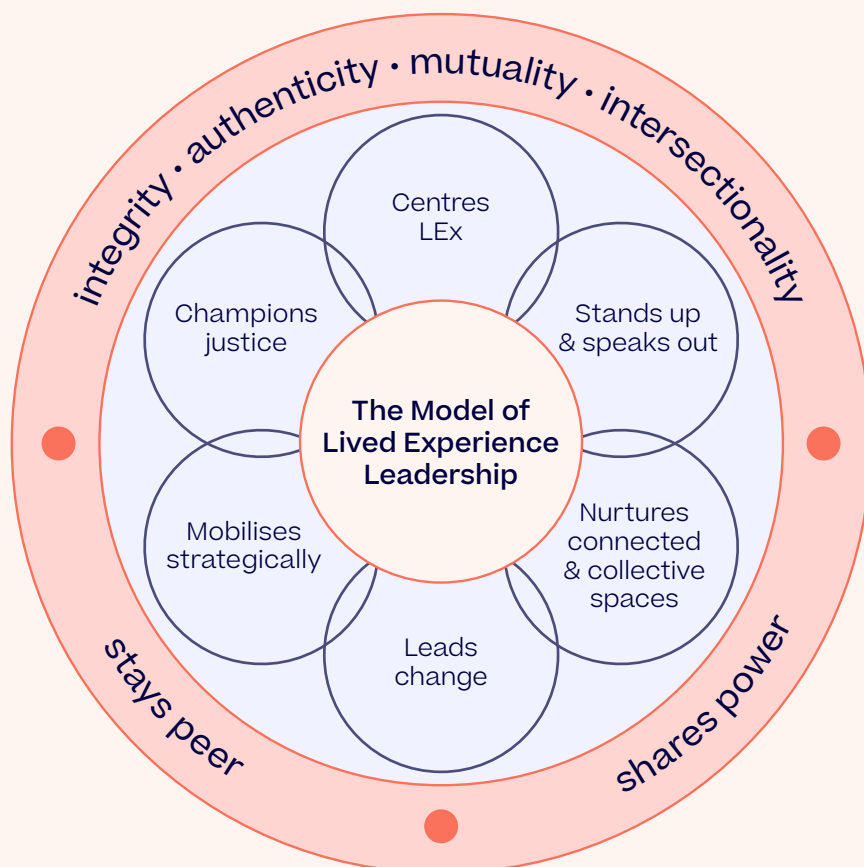
Lived experience leadership takes place in activist, organising, knowledge production, support and service domains.<sup>22</sup> Unrecognised lived experience leadership can include quiet and informal activism, organising and support, work undertaken by people subject to compounded marginalisation, and work undertaken by people who are unable to disclose their lived and living experience in professional contexts.<sup>23</sup>

**Key insight:** Often, lived experience leadership is not named or recognised as such and questions of recognition and credibility constrain thriving lived experience leadership in mainstream contexts.



## Enablers

The Model of Lived Experience Leadership developed by Loughhead and colleagues identifies six key themes and six key values that are characteristic of lived experience leaders:<sup>24</sup>



Adapted from:  
Loughhead et al., A model of lived experience leadership for transformative systems change: Activating Lived Experience Leadership (ALEL) project. 2023.

### Some of the characteristics that enable lived experience leadership include:

- Connections with peers, self, motivation, purpose and allies, alongside meaningful and non-tokenistic opportunities and ownership of the work.<sup>25</sup>
- Leadership by people who have multiple intersecting identities can bring rich insight.<sup>26</sup>
- Mentoring and tailored professional development are important, as are appropriate supervision, support and reflective practice spaces.<sup>27,28</sup>
- Professional development being designed by people with lived and living experience.<sup>29</sup>
- Speaking up and out in the face of the status quo is fundamental to leadership and the work of change agents.<sup>30</sup>
- Strategic mobilisation and allegiance to long-term visions are key enabling factors.<sup>31,32</sup>
- The knowledge of, power of and fidelity to self – as well as community – are fundamental enablers of lived experience leadership.<sup>33</sup>
- Recognition of lived experience leadership as a form of leadership, even when it might not be explicitly named as such.<sup>34,35</sup>

# Emerging insights



Sensemaking to date suggests the following key dynamics in the lived experience leadership space:

## Power and leadership

Notions of power are key to the practice and theorisation of lived experience leadership. In contrast to institutional or hierarchical power, ‘power of self’<sup>36</sup> is a particular kind of power that is both internally generated and externally validated within lived and living experience communities.

**Key insight:** Lived experience leaders work with and transform their own power and power within systems in order to bring about positive change for their communities..

## Palatability politics

People who are considered having ‘radical’ views and those perceived as ‘too challenging’ often have decreased access to formal lived experience leadership spaces, which has been framed in terms of ‘sanitisation’. This can work to exclude and silence the most marginalised, while exceptionalising ‘gold-standard survivors’.<sup>37</sup>

**Key insight:** Systems have limited capacity for embracing difference and views which are considered ‘radical’ are not always welcomed.

## Equity and justice

The literature emphasises the importance of diverse experiences and identities to thriving lived experience leadership, while simultaneously identifying the role that power and privilege play in who gets to occupy ‘official’ lived experience leadership spaces.<sup>38</sup> People subject to multiple oppressions and marginalisation and a diversity of experiences are more likely to have the kinds of lived experience required to lead systems reform, and, concurrently, more likely to be distant from centres of power.

**Key insight:** Compounded oppression and marginalisation constrain lived experience leadership, often leading to the centring of those with existing power and privilege.

## Staying true

People come to lived experience leadership work for a range of reasons, with many motivated by the pursuit of justice in the context of harms experienced within systems.<sup>39</sup> A key challenge for people working within mainstream systems, with the increasing professionalisation of lived experience work, is ‘staying true’ to activist origins and ways of knowing, being and doing.<sup>40</sup>

**Key insight:** Some lived experience leadership contexts make it difficult to stay true to activist roots.

## Embodied leadership, positional authority and continuum thinking

Lived experience leadership continues to be cast in terms of continuum or hierarchical thinking, with formal 'leadership' considered the 'peak' of participation. Collectivist cultures will have different contributions to make in this space, including alternate language and concepts. Currently, the conceptual and academic fields appear to be dominated by Western individualist hierarchical thinking.

***There is a key difference between embodying lived experience leadership and simply occupying a lived experience leadership role.***<sup>41</sup>

**Key insight:** Lived experience leadership continues to be cast in terms of continuum or hierarchical thinking, with formal 'leadership' considered the 'peak' of participation.

## Producing and legitimating knowledge

The sample of lived experience leadership literature considered is primarily produced in Western colonial academic contexts. Knowledges and practices outside this context are yet to be fully recognised, integrated and 'legitimated' as lived experience leadership. The very concept of 'leadership' may be constraining what we understand as systems transformation work and obscuring other ways of being, knowing and doing that affect change in the world.

**Key insight:** Recognising and integrating lived experience leadership outside academic confines is key to expanding the existing knowledge base.

## Contexts of enactment

Lived experience leadership is practiced broadly across a range of settings and within systems of many kinds. Mostly, legitimation of these actions and practices is taking place on the terms and within the contexts of dominant power systems.

***Lived experience leadership continues to be framed in terms of a 'seat at the table' rather than a series of conversations outside the halls of power.***

The decolonising imperative of lived experience leadership seeks to redefine these parameters.

**Key insight:** Lived experience leadership exists inside, outside and beyond institutions.

## Tokenism without supportive structures

Service systems are increasingly being called to account for paternalistic approaches. Some are truly hungry for lived experience leadership and others seem keen to keep pace with sector progress and satisfy stakeholders. To survive within these systems and in the hope of affecting change - principles, practices and people are sometimes compromised. This, in turn can lead to harm, disillusionment, disenfranchisement and lived experience leaders turning away from dominant systems entirely.

**Key insight:** Meaningful lived experience leadership requires practices and systems that are fit for purpose.

## Merit over mechanics

We're often stuck talking about the merits of lived experience without fulsome attention to the mechanics of operationalising lived experience leadership and what needs to change structurally for it to be embedded across systems. This work is starting to occur, but more needs to be done to understand the mechanisms of lived experience systems change focused leadership outside of and beyond mainstream services, structures and organisations.

**Key insight:** Understanding the structural mechanics of embedding lived experience leadership is essential for thriving cultures.

## Professional development for lived experience leaders

Lived experience leadership work requires a specific skill set and the sector needs education to more fully understand, embed and value the role of lived experience leaders. Care should be taken to ensure a dual focus and resist the idea that conventional 'leadership' training for people with lived and living experience will suffice. This runs the risk of situating the 'problem' within people with lived and living experience, rather than highlighting the need for professionals, organisations and systems to collectively broaden and deepen their understanding of lived experience leadership.

**Key insight:** Training for lived experience leaders and non-lived experience leaders, designed by lived experience leaders themselves, is key.

# Conceptualising lived experience advocacy and leadership

## **Our current working definition of lived experience leadership:**

‘Lived experience leadership is a social movement that transforms and restores. It occupies formal and informal spaces, building relationships, coalitions, and movements for change, both within and outside of organisations, systems and institutions. Lived experience leadership recognises the inherently political nature of the personal and works to redress harms caused by epistemic and other types of injustice, including but not limited to colonisation.

Leaders use their lived expertise to change and innovate, creating positive impact for the communities they belong to and represent. Lived experience leadership performs this work by recognising power relations and influencing and enacting broad scale systems change; it involves a re-visioning of the way we conceptualise and operationalise systems and subversion of existing hierarchies that value professional knowledge above lived expertise.’

**This framing will be explored, refined and most likely transformed in the next phase of our work.**

# Next steps

The next phase of the project will be focused on having conversations with the first 10 identified lived experience leaders.

A synthesis of what we hear will inform our second project update, due out in the second quarter of 2024.

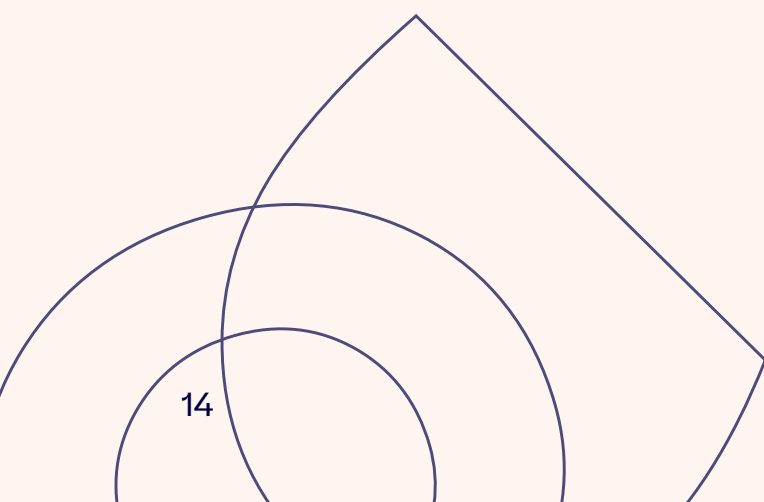
## Get involved

If you would like to be included on our mailing list, receive project updates, or register your interest in participating in project conversations in 2024 please email [on.our.own.terms@rmit.edu.au](mailto:on.our.own.terms@rmit.edu.au)

## Share your thoughts

We would love to hear from you about this project update.

If there is anything you would like to share with us, please email [on.our.own.terms@rmit.edu.au](mailto:on.our.own.terms@rmit.edu.au)



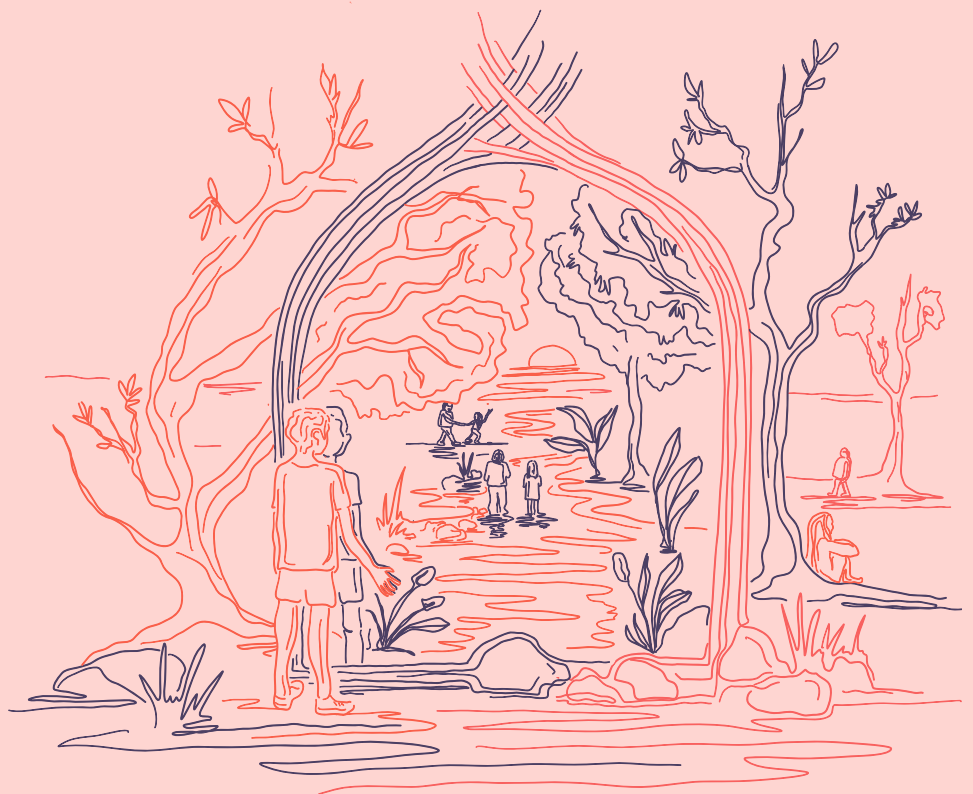
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