



# **The Activating Lived Experience Leadership (ALEL) Project**

# About the ALEL Project

In 2019 the SA Lived Experience Leadership Advocacy Network (LELAN) and UniSA's Mental Health and Suicide Prevention Research and Education Group (MHSPRE) were successful in gaining two years of funding from the Fay Fuller Foundation to establish the Activating Lived Experience Leadership (ALEL) project.

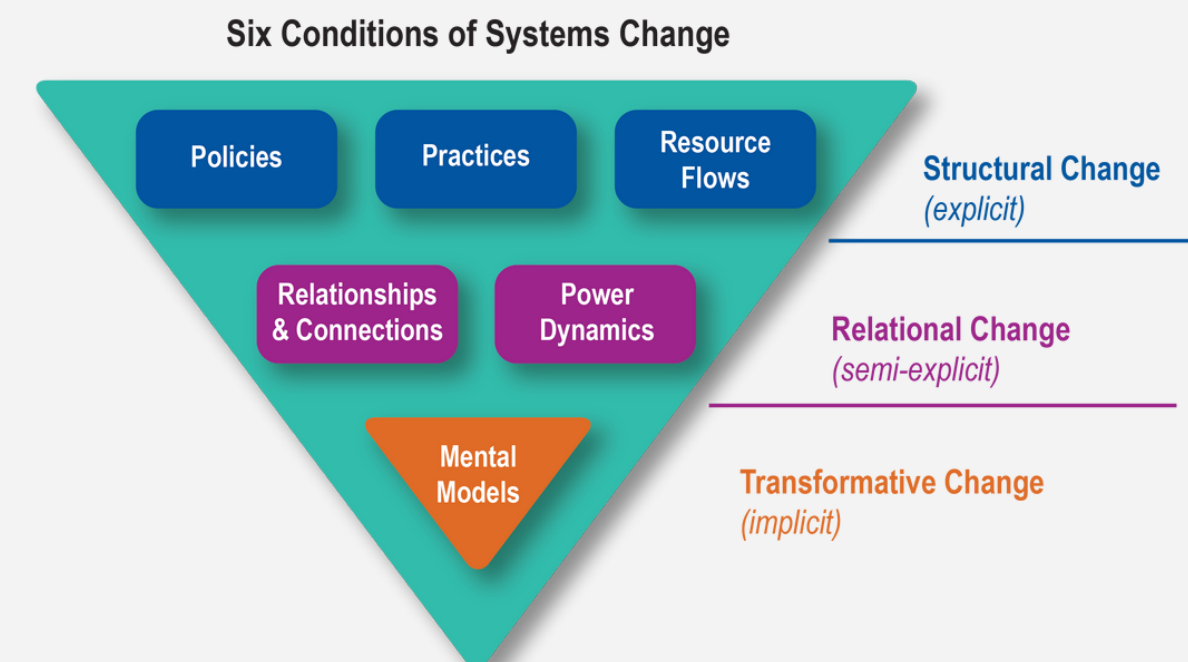
The ALEL project was designed as a participatory action research (PAR) and community development project, bringing people together to improve the way that lived experience leadership is defined, recognised, and utilised at a systems level.



# Our Roadmap

The purpose of *A Roadmap for Strengthening Lived Experience Leadership for Transformative Systems Change in South Australia* is to detail the strategies and processes that organisations can undertake to better recognise, value and embed lived experience leadership across the mental health and social sector ecosystems in South Australia.

The ALEL project intentionally centred on a systems change focus to understand and act on an enduring problem that is mostly felt by people who do not have a positive experience or outcome from mental health service use, and the mental health lived experience movement. Extensive service challenges in mental health systems continue to negatively impact consumers, carers and families across Australia and despite vocal support of lived experience we do not see structures that support it being embedded across South Australia.



# Our Consensus Statement

*The Strengthening Lived Experience Leadership for Transformative Systems Change: A South Australian Consensus Statement* is the result of working with mental health, social sector and lived experience leaders to determine actions we can all take to embed, and leverage lived experience across South Australia.

The Consensus Statement identifies eight priority actions for change. These actions, if followed through, will enable significant shifts across the service systems. If sector leaders and organisations continue with these actions and consider the examples of shared outcomes/measurement, the work towards collective impact will be successful.



The vision for lived experience leadership and future services are where humanity and connection are centred and where people with lived experience meaningfully and equally contribute at all levels, to the point that it becomes the norm.

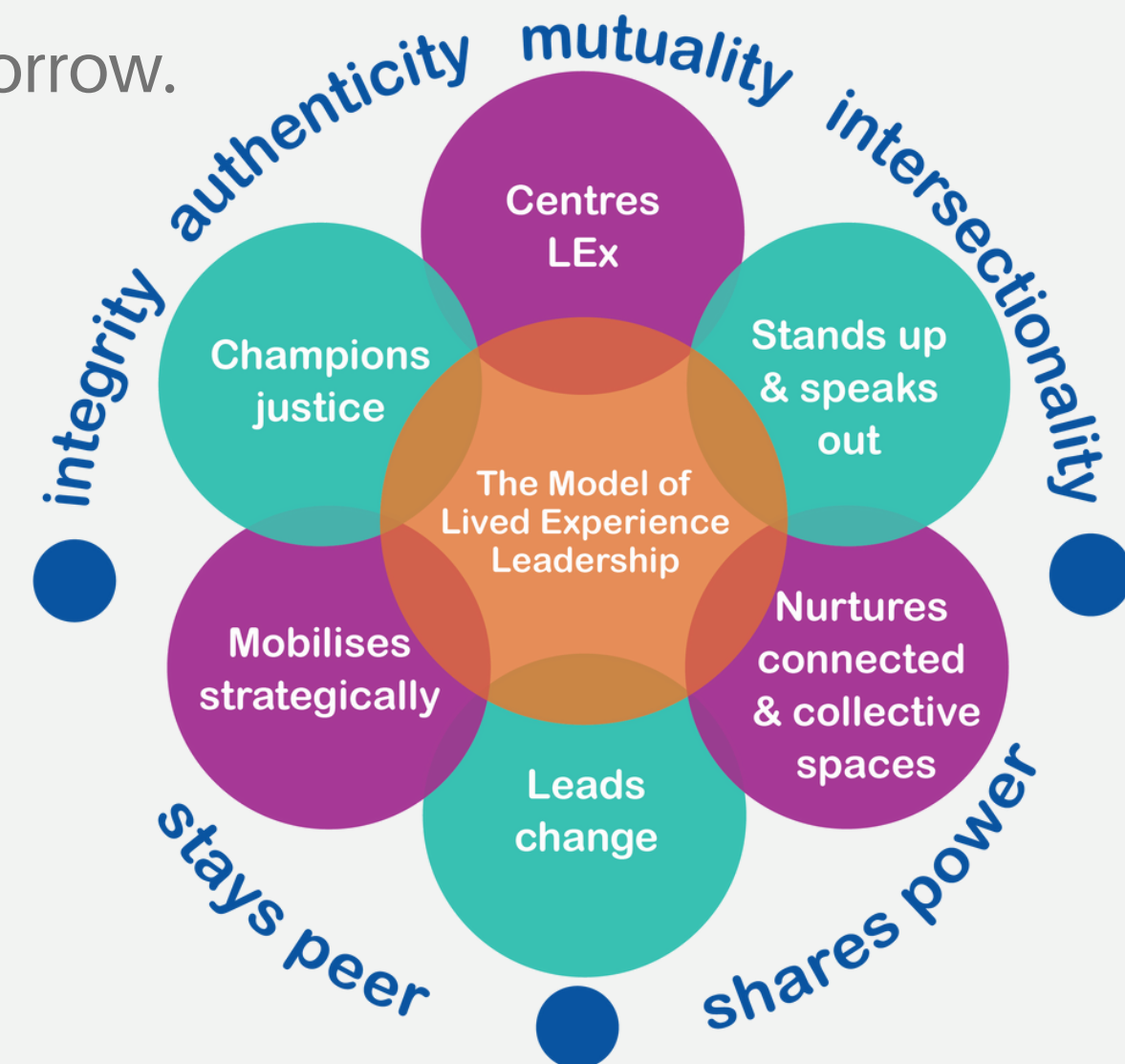


# Our Model of Lived Experience Leadership

*The Model of Lived Experience Leadership* was developed to guide thinking on lived experience leadership and assist reflective learning and growth opportunities for emerging and established leaders.

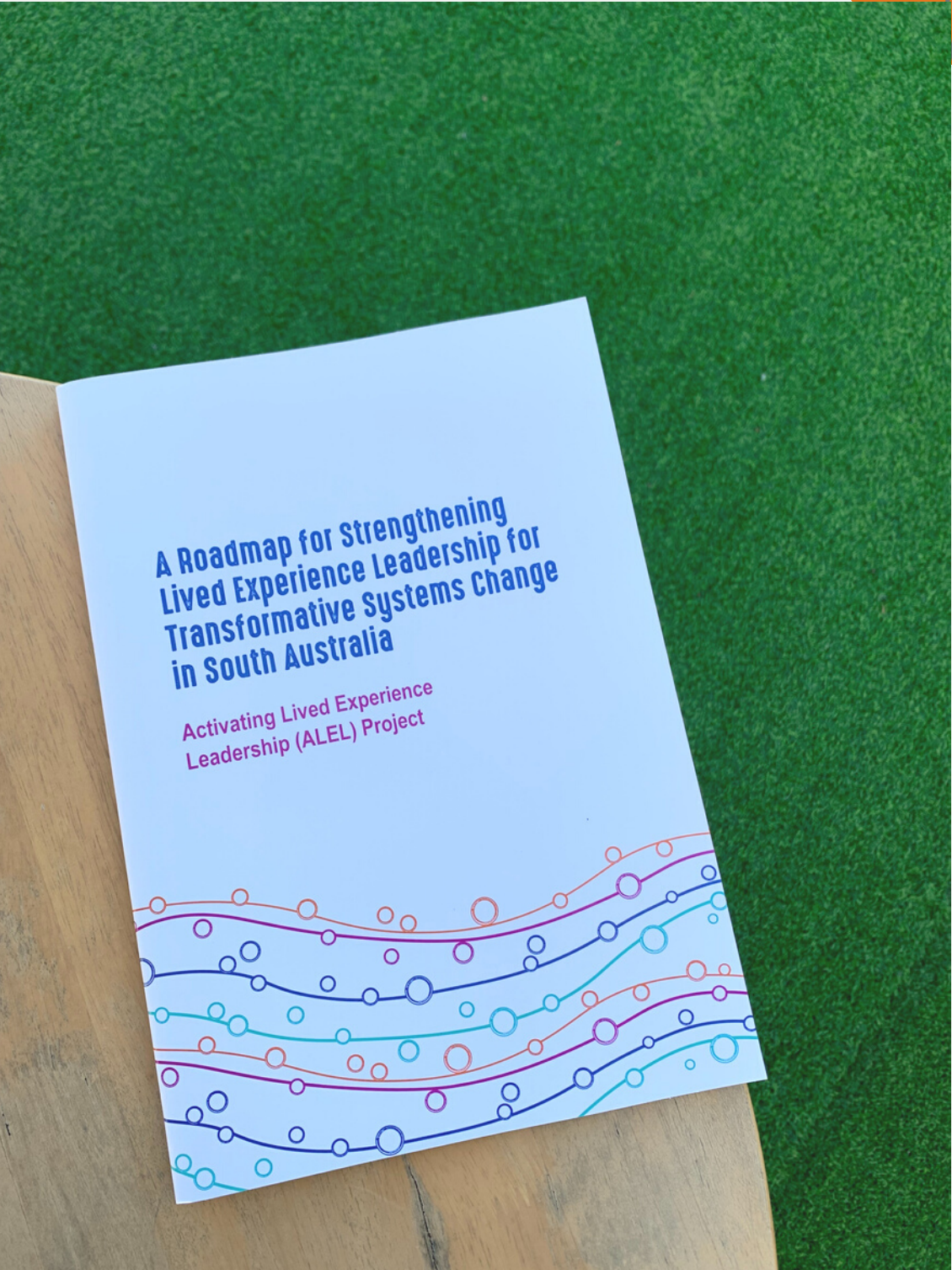
Seeing 'lived experience' as a collective movement allows leaders to recognise that leadership is shared. Individual contributions are always built on the shoulders of others, and they pave the way for who leads with us today and after us tomorrow.

Lived experience leadership is powerful; it is a key lever for transformative systems change that benefits everyone.





# ALEL Project Outputs





# Our Project Outputs



## Strengthening Lived Experience Leadership for Transformative Systems Change: A South Australian Consensus Statement

### Our Vision

We believe unequivocally that now is the time for lived experience leadership to be developed and embedded in our systems. The need is visible and the conditions for change are right. The vision for lived experience leadership and future services are where humanity and connection are centred and where people with lived experience meaningfully and equally contribute at all levels, to the point that it becomes the norm.

Through taking action together a more holistic approach will guide change, and ensure that our language, power, and mindsets, shift beyond biomedical and 'illness' dominated narratives. Upholding rights, giving control to people to determine their own lives and authentic co-design are essential foundations of the changes we seek. Services where people are valued, compassionate care is standard and accountability exists, offer people seeking support a better experience of care and better outcomes for their lives. Systems are strengthened when discrimination and tokenism are minimised and where peoples' dignity is prioritised.

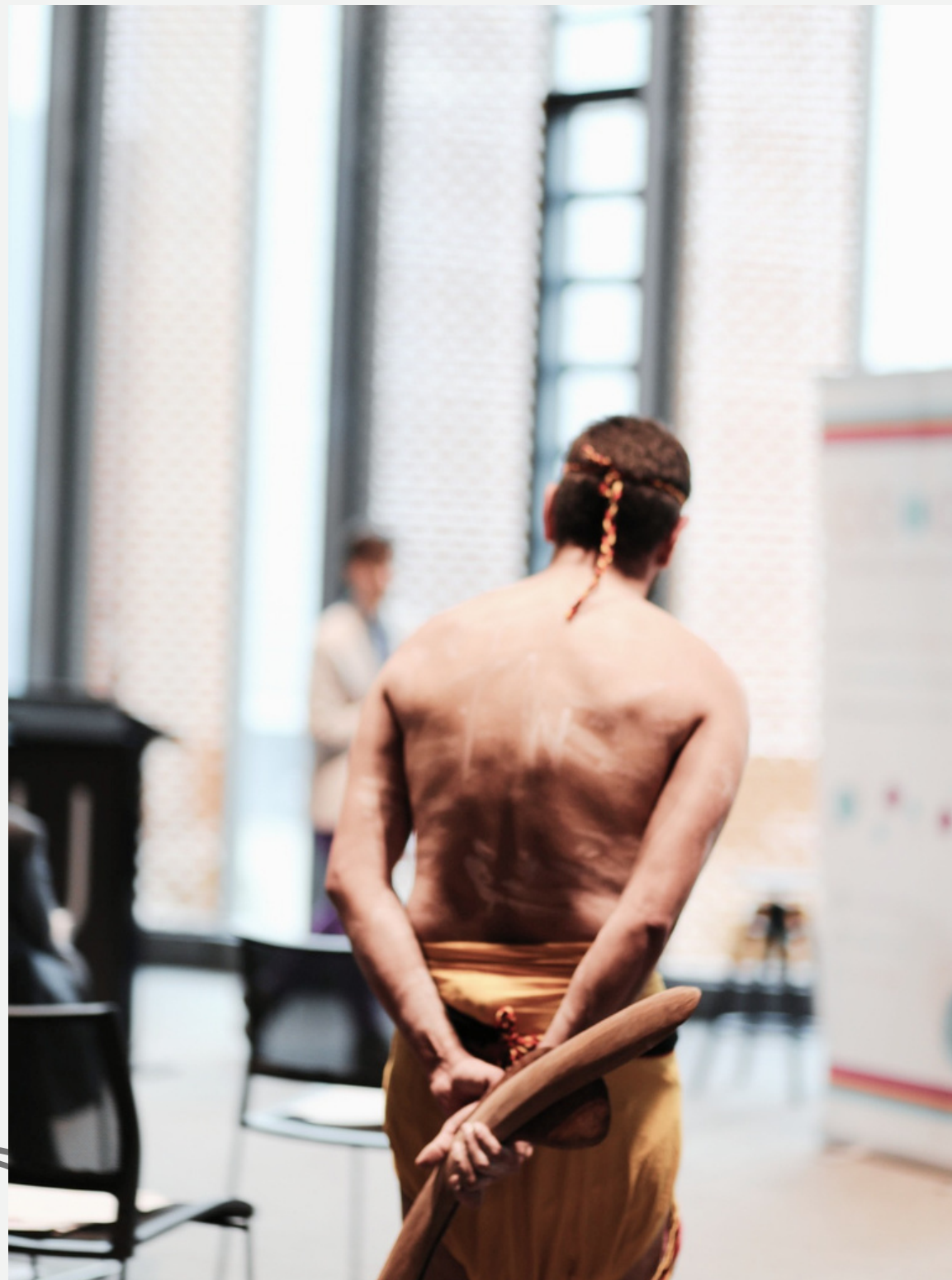
Leadership across the system, including by and with people with lived experience, is core to this vision being realised and is itself a key driver of the broader systems change that the mental health and social services sector require.

### Our Actions

As a collective we believe that the following actions will contribute to fundamental change, and we are committed to bringing them to fruition:

1. Increase the presence of lived experience leaders in governance. Ensure more lived experience designated director positions with boards, statutory councils and commissioning groups.
2. Learning and cultural change programs of lived experience leadership are arranged with executive leaders, staff and communities focussing on diversity of lived experience leadership, supports, preferences and working through stigma and othering.
3. Strengthen learning pathways and leadership skills development for people with lived experience and enable and encourage opportunities for them to lead and provide advocacy. Enable easier access to professional development and formal qualifications.
4. Fund leading lived experience organisations to develop and deliver networking activities, including coordination of information, activities and events that support local lived experience leadership, community initiatives and voice across diverse population groups. Focus on intersectionality.
5. Enable resource flows for meaningful co-production of all services and programs. This should include training of co-production facilitators and chairpersons, and funding equal places at the table for lived experience advisors and leaders.
6. Promote lived experience leadership and accountability measures through service agreements, KPIs and, where appropriate, regulatory frameworks and legislative processes.
7. Ensure models of care include equal recognition of lived experience workforces and peer support.
8. Ensure range of organisational and sector infrastructure for the effective recognition, valuing and embedding of the lived experience workforce.









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Lived experience is a key and growing driver of the development of the mental health system (and beyond).

People who have experienced mental health challenges and use mental health services bring a personal recovery focus and the perspectives of supporting one through mental health challenges.

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**HONOURABLE  
STEPHEN WADE WLC**  
*Minster for Health and Wellbeing*



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Lived experience leadership needs to be developed and embedded into our systems. Upholding rights, giving control to people to determine their own lives as much as possible and authentic co-design are essential foundations of the changes sought by people with lived experience.

— **HONOURABLE  
STEPHEN WADE WLC**

*Minster for Health and Wellbeing*



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Aligned to the Mental Health Services Plan, this is the vision for services where people are valued, compassionate care is standard, and people are supported to a better experience of care and better outcomes for their lives. Systems are strengthened when discrimination and tokenism are confronted and where people's dignity is prioritised.

This system transformation will be realised through the collective work of people with lived experience and sector leaders - who then share 'system power' to the benefit of everyone.



— **HONOURABLE  
STEPHEN WADE WLC**  
*Minster for Health and Wellbeing*





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I think that having a lived experience and being able to utilise it this way is one of the greatest things because you're able to turn what was such a relentlessly bad experience into a positive.

You're able to salvage beauty from the ashes of your experience; you've come out of the fire and you're all refined, and all the other metaphors you want to use.



—— **LIVED EXPERIENCE LEADER**









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It's the difference between working from your head only and working from your heart as well.

—— **SECTOR LEADER**

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We increasingly hear this in spaces about designated lived experience and non-designated lived experience roles and are they the same, and can we just conflate the two?

— **ELLIE HODGES**

*Executive Director of LELAN*  
ALEL Project Lead





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Let's talk about that briefly because this person, a sector leader shared, *'Some of the best lived experience leaders that I know wouldn't identify with that label, and their lived experience is often silent.'*

Absolutely true, but it's not the same. I've been a leader in community and in organisations. I've also been a lived experience leader. The latter is the hardest work I've ever done. Personally and professionally. The toll that it takes.



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**ELLIE HODGES**

*Executive Director of LELAN*  
ALEL Project Lead





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I definitely do not self-identify as a leader, but other people see me that way which is both confusing and challenging for me. I'm coming to realise, through this project and others, that my inability to perceive myself as a leader and take on that role is actually inhibiting my ability to be effective in some ways.

Maybe the fact that I come from the margins has taught me that I have no right to be a leader – that someone with mental illness, disability, lower class, limited education, LGBTIQ+ has nothing to offer in leadership spaces.

—— **LIVED EXPERIENCE LEADER**





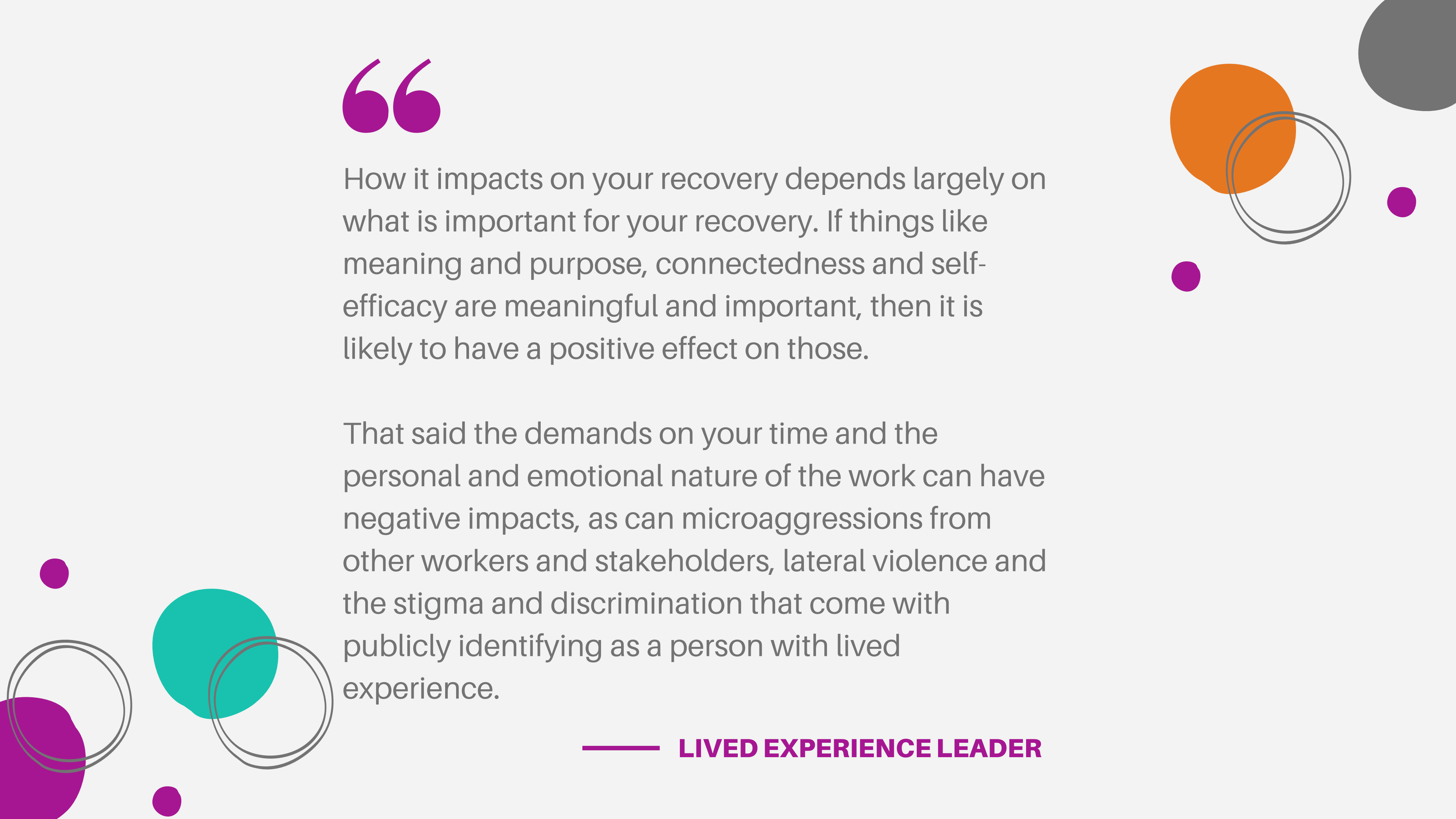




How it impacts on your recovery depends largely on what is important for your recovery. If things like meaning and purpose, connectedness and self-efficacy are meaningful and important, then it is likely to have a positive effect on those.

That said the demands on your time and the personal and emotional nature of the work can have negative impacts, as can microaggressions from other workers and stakeholders, lateral violence and the stigma and discrimination that come with publicly identifying as a person with lived experience.

—— **LIVED EXPERIENCE LEADER**





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There is a real opportunity for us in South Australia to make shifts in the system, to end practices which can marginalise, exclude and limit our lives.

This can occur by embracing these actions collectively, to commit to them and resource them as a way of generating a culture of shared leadership and recovery values.

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**MARK LOUGHHEAD**

*Lecturer - Lived Experience, UniSA*  
ALEL Research Lead





While there is an emphasis on collaboration and shared agendas, The Roadmap identifies that there are also times when lived experience leaders should be doing the leading and for others to take a position of listening and learning. This is one of the central understandings of lived experience leadership.

It's not just about inclusion, but about recognising that experienced and skilled leaders can design, organise, and manage services.

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**MARK LOUGHHEAD**

*Lecturer - Lived Experience, UniSA*  
ALEL Research Lead



We end on a vision of services which are about recovery and achieving connection and citizenship. When life is at its hardest, and you're just struggling to get through the day, or the hour, you need help that really works for you.

When your mind isn't working for you, you need compassion and understanding, confidence and reassurance that you can reconnect to your life, what you want to do and what your life can become. You need resources and new practices to help you. You can't let assumptions about prognosis, stigma or behaviour get in your way. You need a sense of control and to have agency and dignity recognised.

We need services that reflect these recovery values, and we need opportunities to learn from each other, and the best that health professionals have to offer in supporting our journeys.

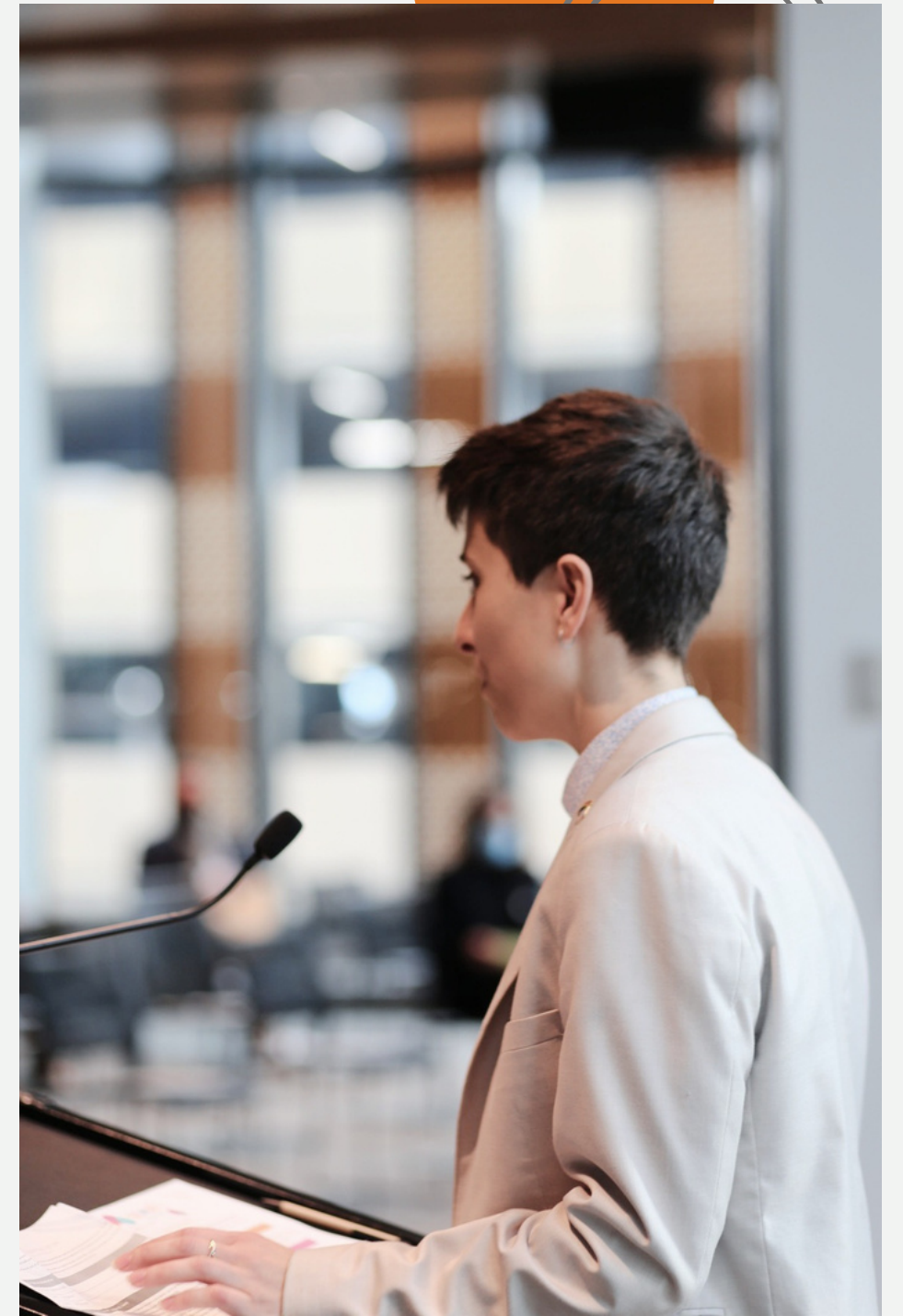
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**MARK LOUGHHEAD**

*Lecturer - Lived Experience, UniSA*

ALEL Research Lead







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It was a collective project and that was what was really inspiring for me.

**BROOKE BICKLEY**

*Lived Experience Leader*  
ALEL PAG Member







Two of the things I'd like to see happen is more opportunities for professional development for those who are wanting to enter the lived experience workforce or those already in the lived experience workforce. I see that as an area that's lacking.

I'd also like to see more formal and informal networking opportunities for those in the lived experience workforce.

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**BROOKE BICKLEY**

*Lived Experience Leader*

ALEL PAG Member



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This is a watershed piece of work. For a long time, we've talked about a lot of problems in mental health and a lot of them just haven't had the space to be resolved.

I think this work and our responses to it can create that space. This is a great piece of work to show us the way forward, so I'm really excited by what comes next.

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**GEOFF HARRIS**

*Executive Director of Mental  
Health Coalition SA  
ALEL PAG Member*





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One of the things the Minister talked about is that we do have a Mental Health Services Plan and there's a lot of work to do about that. This piece of work is really critical to how we do that.

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**GEOFF HARRIS**

*Executive Director of Mental  
Health Coalition SA  
ALEL PAG Member*



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One of the things that struck me about the project was thinking of this as a social movement so it's not just the mental health angle.

This project puts the human back into the puzzle book. In some areas of the work we've got in front of us, that's critical to actually not just solving part of the problem in one place, or in one of the silos.

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**GEOFF HARRIS**

*Executive Director of Mental  
Health Coalition SA  
ALEL PAG Member*











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We need people to actually commit and say, *'This lived experience leadership stuff is valuable; we're going to put some money at this and make sure that it happens, and it happens properly.'*

—— **LIVED EXPERIENCE LEADER**





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Having this roadmap and having the evidence base to show that people with lived experience in positions of being able to have a voice and being able to bring that to the table is really essential.

— **HEATHER NOWAK**

*Lived Experience Leader*

*SA Mental Health Commissioner*





Our challenge in public mental health is to listen  
and really create some space for that.

—— **HEATHER NOWAK**  
*Lived Experience Leader*  
*SA Mental Health Commissioner*









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The critical element of this is leadership.

Many of us have worked alongside people with lived experience. We've had people with lived experience in our wards and in our services. This takes us to a different space ... a different place. That is people with lived experience as leaders in our system and really demonstrating for us how things should look and feel.

— **LIZ PROWSE**

*Director - Mental Health Policy,  
Planning and Safety at Office of  
the Chief Psychiatrist*





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I am very acutely aware that we cannot do the same that we have done for the last 30 years. It needs to look different and this is one of the things that might help us take a few steps in the right direction.

I'm very happy to add my energy and enthusiasm to any conversation and discussion that helps move this forward.

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**LIZ PROWSE**

*Director - Mental Health Policy,  
Planning and Safety at Office of  
the Chief Psychiatrist*

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How lived experience is opening up fresh ways of knowing and fresh sightlines of understanding. All of these things for clinicians, for people in policy, for people in teaching.

I'm seeing that happen right now. We just gotta make it happen on scale. We can't just make that happen in small pockets.

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**NICHOLAS PROCTER**

*Chair - Mental Health Nursing &  
Director of the Mental Health and  
Suicide Prevention Research and  
Education Group, UniSA*







I champion for the underdog, the unheard, the vulnerable, the ones who can't speak out.

—— **LIVED EXPERIENCE LEADER**

# Two-Year Strategic Partnership Announced

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The strategic partnership between LELAN and the Foundation will see us working together to influence broad systems change that enables lived experience leadership to thrive, and to support LELAN in their role as the peak body for lived experience leadership in South Australia.

— **NIALL FAY**

*Chief Executive Officer of  
Fay Fuller Foundation*







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Whilst today is a culmination and a bringing together and a public sharing of the work that we've done, this is really a start to get the systems change that this is really about and that the vision is for.

We have to bring accountability to the system, be the strongest advocates to get this implemented, not just be a beautiful document that collects dust.

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**ELLIE HODGES**

*Executive Director of LELAN  
ALEL Project Lead*





**download key documents and read more at  
[www.lelan.org.au/alel](http://www.lelan.org.au/alel)**





# **Thank you to the ALEL Project Team and Project Advisory Group (PAG)**

## **ALEL Project Team**

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Heather McIntyre, Research Assistant  
Nicholas Procter, Research Governance

## **ALEL PAG**

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Julia McMillan	Tayla
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[www.lelan.org.au](http://www.lelan.org.au)