



More Than a Story

Gathering Suicide Lived and Living Experience with Safety and Purpose
Churchill Fellowship 2023

Cover Photo:

A quilt made by Lynn Barnard following the loss of her son. During my stay with Ken and Lynn in Inglewood, South West Sydney, Lynn shared how quilting became a way to process grief and hold memory. Creative practices such as this reflect how lived and living experience can be expressed and shared beyond words.

the
CHURCHILL
fellowship

***“Remember,
Talk to us, not about us.”***

Glen Cotter

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FOREWORD

I am absolutely delighted to provide a foreword to Maria's Churchill Fellowship Report. Having followed her work for a number of years, it is inspiring to see her recent tireless efforts come to fruition.

In the 30 years I've been involved in suicide prevention, nothing has raised government and societal awareness more than the voices of people with lived and living experience service-users, patients, parents, siblings, carers, and many many others. Their contributions have been fundamental in improving research, policy, and practice. Yet despite this progress, we still lack clear evidence on how best to involve people safely, ethically, and effectively.

Over a decade ago, I visited colleagues in Australia and was struck by how they were leading the way in real-world involvement. Maria has drawn on this expertise through extensive fieldwork and interviews, and she brings it together with sensitivity and rigour.

Her analysis shows that effective involvement depends not only on the skills and readiness of individuals, but also on the readiness of organisations themselves. Maria highlights a number of powerful themes and principles – for example, building safety into the process from start to finish and the importance of shared leadership.

This report represents an important and much needed contribution. Her practical framework for involvement will strengthen suicide prevention in the UK and internationally and ultimately save lives.

**Nav Kapur MBChB, MMedSc, FRCPsych, MD, FRCGP (Hon), Professor of Psychiatry and Population Health,
University of Manchester, England, March 2026.**



EXECUTIVE SUMMARY

This Churchill Fellowship explores how suicide Lived and Living Experience (LLE) can be gathered safely, ethically and meaningfully, so that people are supported and their insight leads to real change.

Across the UK and Australia, Lived and Living Experience is recognised as essential to suicide prevention. However, there is still limited practical guidance on how to involve people well, particularly in relation to safety, purpose and accountability.

This report draws on fieldwork in Australia, including over 40 interviews, national conferences, and collaboration with organisations such as Roses in the Ocean, StandBy Support After Suicide and Mental Health First Aid International, alongside UK sector insights.

The findings show that safe and meaningful involvement requires more than participation alone. It depends on preparation, clear purpose, shared decision-making, inclusive language and organisational readiness.

The report identifies seven themes for best practice and sets out a clear direction for change. Its central recommendation is a UK framework and practice standard, supported by training, tools, commissioning requirements and sustainable workforce structures.

Seven Themes for Best Practice Emerged:

- 1 SAFETY FIRST: Supporting those who share**
Building emotional and psychological safety before, during and after involvement
- 2 MORE THAN A STORY: Purposeful Practice**
Gathering experience with clarity, clear purpose and accountability
- 3 RETHINKING THE WORKFORCE: Working while Healing**
Supporting lived experience roles with flexibility, training, supervision and wellbeing
- 4 SHARING POWER: From Inclusion to Partnership**
Embedding lived experience in co-design, leadership and decision-making
- 5 WORDS SHAPE WORLDS: Language and Narrative**
Using language that fosters inclusion, belonging and respect
- 6 CONTEXT MATTERS: Identity, Culture and Community**
Recognising how identity, culture and local context shape safety and participation
- 7 MAKING IT REAL: Embedding Lasting Change**
Turning lived experience input into sustained policy, organisational and service reform

Main Recommendations

- 1** Develop national guidance and a practice standard for safe, ethical and meaningful suicide Lived and Living Experience involvement.
- 2** Build workforce capability through training, supervision and support for contributors, professionals and organisations.
- 3** Move from consultation to partnership, embedding Lived and Living Experience in co-design, leadership and decision making.
- 4** Align policy, commissioning and funding with clear standards for Lived and Living Experience involvement.
- 5** Create sustainable roles, support structures and pathways that enable people to contribute safely over time.

Safe engagement with people who have Lived and Living Experience requires clear purpose, shared responsibility, and systems that value wellbeing alongside influence. Trauma-informed approaches were consistently identified as the foundation for effective partnership.

Contributors emphasised that Lived and Living Experience, whether through suicidality, supporting others, or bereavement, must be treated as expertise rather than testimony. When gathered with care, it drives innovation, strengthens trust, and improves services. When mishandled, it risks re-traumatisation and disconnection.

The report offers a practical framework for England informed by Australian learning. It recommends developing national guidance for gathering suicide LLE, embedding trauma-informed principles across engagement, commissioning and research, supporting suicide-specific peer roles with appropriate supervision, and ensuring funding frameworks recognise LLE as professional expertise.

This Fellowship demonstrates that meaningful inclusion of suicide lived and living experience is both possible and transformative. When gathered safely and purposefully, it strengthens systems, deepens understanding, and likely saves lives.

***“The could have’s
the should have’s
the if-only’s
interlaced with extreme shock, anxiety, PTSD, bereavement, depression,
themes common with suicide loss.”***

INTRODUCTION AND SCOPE

This Churchill Fellowship explores how suicide-related Lived and Living Experience can be gathered safely, ethically, and meaningfully, so that people who share their experience and those who listen, are both supported and protected. Across Australia and the UK, there is growing recognition that understanding lived and living experience, including suicidality, bereavement, and caring for others, is essential to suicide prevention. However, there remains limited practical guidance on how to involve people well. This Fellowship set out to identify the principles and conditions that make such engagement safe, purposeful, and effective. Fieldwork in Australia included more than 40 interviews with people with lived and living experience, peer workers, organisational leaders, academics, and advocates.

My motivation for this work is both professional and personal. Over more than a decade working in suicide prevention and bereavement support, I have seen how people's experiences are often sought with good intent, but without the preparation or support required to facilitate safely. I also bring my own experience of suicidality and bereavement, and know first-hand that sharing can be both healing and exposing.

This Fellowship is grounded in deep respect for those who contribute, and a commitment to ensuring their involvement is handled with care, consent, and impact.

Before travelling to Australia, I spoke with UK colleagues and organisations to identify the challenges they most needed addressed. Many described uncertainties about how to gather lived experience safely, manage consent and boundaries, and provide appropriate support.

These conversations shaped the focus of the Fellowship and ensured the learning would be relevant to UK policy and practice.

Australia was chosen because of its progress in embedding suicide LLE across suicide prevention and bereavement systems, including suicide-specific peer roles and organisational readiness. Fieldwork in 2025 involved more than 40 in-depth interviews across five regions (Sydney, Brisbane, Sunshine Coast, Melbourne, and Perth) with people with lived and living experience, peer workers, organisational leaders, academics, and advocates, alongside learning from key national sector events.

All material was analysed thematically using trauma-informed and systemic principles, recognising that suicide LLE may involve ongoing vulnerability and that organisations hold shared responsibility for safety.

Findings are presented through seven themes and translated into practical guidance, framed through a UK lens to support national application.

This report is intended for people with Lived and Living Experience of suicide; suicide prevention leads in public health and Integrated Care Systems; peer workers and advocates; researchers and academics; policy-makers and elected representatives responsible for national and local suicide-prevention strategy; commissioners and funders; voluntary, community, and lived-experience-led organisations; and professionals involved in service design, delivery, training, and programme development.

Ultimately, this Fellowship is about strengthening how lived and living experience informs suicide prevention, not as an add-on, but as an integral part of how systems think, design, and respond.

AUTHOR BIOGRAPHY

Maria Roberts is a public health leader specialising in suicide prevention, bereavement and Lived and Living Experience.

She has over ten years' experience working across local and central government, including the Office for Health Improvement and Disparities (OHID) and Public Health England, as well as NHS England, alongside roles in the voluntary sector. Her work has focused on leading programmes, qualitative research and system change initiatives to improve support and outcomes for individuals and communities.

Maria has extensive experience in suicide prevention, including her work with Suicide Bereavement UK, Samaritans and NHS partnerships. She has led research and engagement programmes that centre Lived and Living Experience, and has contributed her own experience through speaking at conferences, advisory roles and participation in boards and networks. Her approach combines professional expertise with personal insight, including bereavement.

Maria was awarded a Winston Churchill Fellowship in 2023 to explore best practice for gathering suicide Lived and Living Experience. She undertook the primary research in Australia in 2025, alongside additional interviews in the UK to inform the national context. This report brings together insights from over 50 interviews, with the aim of supporting safer, more ethical and more effective approaches to involving Lived and Living Experience in policy and practice.



***“When people ask for your story,
they need to understand it’s not just education,
it’s your life.
That deserves care and respect.”***

Chris Cuttone

UK CONTEXT: EXISTING GUIDANCE AND GAPS

Across the UK, there is growing recognition that people with Lived and Living Experience of suicide have a vital role to play in shaping suicide prevention policy, services and systems. National guidance increasingly emphasises involvement, partnership and co-production as core principles of effective prevention and postvention work.

Alongside this policy intent, there is strong evidence that people are willing to contribute their experiences when opportunities are created for them to do so. Large-scale initiatives such as the *From Grief to Hope* report^[1] demonstrate the strength of collective voice when people feel able to come forward. Produced by the University of Manchester in collaboration with the Support After Suicide Partnership, *From Grief to Hope* is the largest expression of lived and living experience of suicide bereavement ever undertaken internationally. More than 7,000 people shared their experiences, clearly demonstrating the appetite to contribute voices that can inform policy and improve support.

Together, national policy intent and public participation suggest a sector that understands why lived and living experience matters. What remains less clear is how this involvement should be undertaken in practice, particularly in ways that are safe, consistent well-supported and impactful.

Policy Commitments and Gaps in Practice:

National policy increasingly emphasises inclusion. The NICE Suicide Prevention Guidelines^[2] recommends that local partnerships involve people affected by suicide in both the planning and delivery of suicide prevention activities:

“Include people who have been affected by a suicide attempt or bereaved by suicide (such as those from affected communities) in the planning and delivery of suicide prevention activities.

Similar expectations are reflected in NICE’s Quality Standard QS189^[3], the Suicide Prevention Strategy for England^[4] and OHID’s Local Suicide Prevention Planning Resource^[5].

Collectively, these national documents articulate who should be involved and why lived and living experience is valued, but they provide limited practical guidance on how involvement should be carried out safely or meaningfully.

There is little detail on organisational readiness, emotional safety, preparation, training, supervision or ongoing support for those contributing their lived and living experience, or for the professionals and facilitators responsible for supporting and holding this work. As a result, strong policy intent is not consistently matched by the infrastructure required to translate expectations into practice.

“As we are all expected to involve people with lived experience/work in co-production, it would be really beneficial to have guidance in place so those with lived experience receive the right respectful reception and there is appropriate support in place before, during and immediately following their involvement. Safety should be a built-in consideration particularly when many are sharing traumatic experiences in their lives.”

Adele Owen, Suicide Prevention Programme Coordinator in Greater Manchester

¹ McDonnell et al., *From Grief to Hope*, 2020

² NICE, *Preventing suicide in community and custodial settings (NG105)*, 2018 (updated 2023)

³ NICE, *Suicide prevention: Quality Standard (QS189)*, 2019

⁴ Department of Health and Social Care, *Suicide prevention strategy for England: 2023 to 2028*, 2023

⁵ Office for Health Improvement and Disparities, *Local suicide prevention planning: A practice resource*, 2020

UK interviews and sector reflections

These gaps between policy and practice were consistently reflected in interviews with UK colleagues.

Participants recognised the growing need to meaningfully involve and partner with people with suicide Lived and Living Experience across policy, research and practice, describing this partnership as essential to ensuring that suicide prevention activity is safe, compassionate and effective. While the value of lived and living experience involvement is now widely recognised, the mechanisms to ensure it happens safely and consistently are still evolving.

Participants described goodwill, creativity and commitment within a system that remains **fragmented, under-resourced and lacking clear national frameworks or guidance** to support professionals in doing this work well.

Adele Owen, Suicide Prevention Programme Coordinator in Greater Manchester, and Sue Willgoss, who lost her autistic son to suicide and now works as an Advisor for Suicide Prevention and lived experience within the NHS, both highlighted the **policy-practice gap**. They noted that while national policy increasingly requires lived and living experience involvement, there remains a lack of consistent national infrastructure and practical guidance to prepare audiences, speakers and systems safely.

Numerous UK participants warned that professionals often want to engage LLE but are unsure how to begin, noting that ‘perfection can become the enemy of progress’. Sue Willgoss emphasised the importance of lived and living experience being “valued not only in words but through fair and timely recognition”.

This tension was captured clearly by Paul Vittles, Suicide Prevention Consultant and Facilitator with Lived Experience, and Co-Founder of the Zero Suicide Society, alongside Professor Nav Kapur from the University of Manchester, who spoke of **‘intent without infrastructure’**, urging greater alignment between research, policy and service delivery so that learning from lived experience meaningfully informs practice.

Members of the National Institute for Health and Social Care Research (NIHR), Greater Manchester Patient Safety Research Collaboration (NIHR GM PSRC), University of Manchester’s, Lived Experience Advisory Group, led by Dr Leah Quinlivan, reflected on past experiences of being invited to share at other organisations without sufficient preparation, support or follow-up. They contrasted this with the group’s current culture of safety and respect, where contributors are supported throughout and treated with care.

Together, these conversations highlight a sector rich in commitment but constrained by fragmented funding, limited infrastructure and uneven support. **There is strong appetite for national frameworks that build on existing work and embed lived and living experience ethically, safely and with purpose.**



Manchester Piccadilly Gardens, UK

Third-sector and local practice

In the absence of detailed national guidance, third-sector organisations and local partnerships have led much of the innovation in this space, developing practical tools and frameworks to support safer and more ethical involvement of people with lived and living experience. These are not consistently available at a national level.

The National Suicide Prevention Alliance (NSPA) has made particularly strong progress in this area.

The NSPA is a cross-sector alliance of public, private and voluntary organisations, funded in part by the Department of Health and Social Care and hosted within the mental-health charity sector.

While it is not a government-led body, it has played a leading role in developing practical tools, learning opportunities and networks focused on lived and living experience involvement.



Arriva London bus, Waterloo, UK, 2025

Jess Worner, Lived Experience Network Manager, NSPA, explained that the Alliance's work has grown in response to the lack of consistent national guidance:

“We developed the Lived Experience Network and practical resources because there was little support available for organisations to involve people safely and meaningfully. There's been a lot of progress, but we're a small team and more resource is needed to properly embed this work across suicide prevention.”

Examples of this work include NSPA's resource Involving People with Lived Experience in Suicide Prevention and Bereavement Support,^[6] and its consultancy and learning offers for organisations, and events delivered through the Lived Experience Network.

These initiatives represent meaningful progress, though further investment and nationally coordinated frameworks are still needed to embed such approaches consistently across the UK.

As well as the NSPA's work, additional guidance and tools have been developed by the Support After Suicide Partnership (SASP), which draws on the 4Pi Standards to support clarity of purpose, presence, process, principles and impact.^[7] The NIHR INVOLVE Standards^[8], while developed for research contexts, are also widely used and adaptable to suicide prevention activity.

Further examples include Leeds Mind's guidance on language, support and trauma-informed practice^[9], and practical preparation and post-speaking support developed by the Public Health Agency in Northern Ireland^[10].

Together, these examples demonstrate strong local and sector-led practice. However, **they are not underpinned by a unified national framework, resulting in variation in approach, quality and consistency across regions and organisations.**

6 National Suicide Prevention Alliance & Support After Suicide Partnership, Involving people with lived experience in suicide prevention and bereavement support, 2023

7 Support After Suicide Partnership, Postvention guidance and resources, drawing on National Survivor User Network, 4Pi National Involvement Standards, 2015

8 National Institute for Health Research, UK Standards for Public Involvement, 2018

9 Leeds Mind, Language, support and trauma-informed practice guidance, n.d.

10 Public Health Agency Northern Ireland, Guidance on preparation and post-speaking support, 2017

Funding and investment

The challenges described by participants are shaped not only by culture and practice, but also by funding structures that determine what is possible, sustainable and safe. Several interviewees highlighted how short-term funding models affect the sustainability of lived and living experience roles and projects and place additional emotional demands on those working in suicide prevention. Compared with Australia's longer-term investment model, UK suicide prevention funding remains characterised by short cycles, variable access and limited ring-fenced support for lived and living experience workforce development.

Amelia Wrighton, CEO and Co-Founder of Suicide & Co, identified short-term funding as a key barrier and described the emotional labour carried by bereavement supporters working within insecure funding environments.

Within this context, **in England the £10 million VCSE Suicide Prevention Grant Fund^[11] represents a positive commitment** but remains time-limited and modest relative to need, with no confirmed continuation beyond 2025. This short-termism affects the sustainability of lived and living experience roles and often limits investment in training, supervision and ongoing support structures.

In Scotland, Wales and Northern Ireland, suicide prevention funding is primarily embedded within national strategies and delivery plans rather than provided through discrete competitive grant funds. While this enables system-wide alignment and national coordination, it can also reduce transparency around levels of investment in lived and living experience activity and limit direct access to funding for voluntary and community sector organisations.

Funding Context: UK and Australia

Australia's suicide prevention system is supported by multi-year national and state investment programmes, which enable longer-term planning, workforce development and sustained lived and living experience roles.

In contrast, **UK funding is typically time-limited and fragmented across nations, and embedded within broader strategies rather than supported by dedicated, long-term funding streams.** This shapes how lived and living experience can be gathered, supported and sustained.

System Investment Approaches

Australia and the UK:

AUSTRALIA

National Suicide Prevention Leadership and Support Program^[12]

National Mental Health and Suicide Prevention Plan^[13]

State-based suicide prevention investment frameworks (incl Victoria, New South Wales)^[14]

ENGLAND

VCSE Suicide Prevention Grant Fund^[15]

NHS Long Term Plan and suicide prevention-related investment^[16]

SCOTLAND

Creating Hope Together – Scotland's Suicide Prevention Strategy and Delivery Plan^[17]

WALES

Suicide Prevention and Self-Harm Strategy and Delivery Plan for Wales^[18]

NORTHERN IRELAND

Protect Life 2 Suicide Prevention Strategy and associated Action and Implementation Plans^[19]

11 Department of Health and Social Care, VCSE Suicide Prevention Grant Fund, 2023

12 Australian Government, National Suicide Prevention Leadership and Support Program, 2022

13 Australian Government, National Mental Health and Suicide Prevention Plan 2021–2031, 2021

14 Government of Victoria; Government of New South Wales, State suicide prevention frameworks, various years

15 Department of Health and Social Care, VCSE Suicide Prevention Grant Fund, 2023

16 NHS England, NHS Long Term Plan, 2019

17 Scottish Government, Creating Hope Together: Scotland's Suicide Prevention Strategy 2022–2032, 2022

18 Welsh Government, Suicide Prevention and Self-Harm Strategy for Wales 2025–2035, 2025

19 Department of Health Northern Ireland, Protect Life 2 Suicide Prevention Strategy, 2019

International guidance and learning

International frameworks offer examples of the operational clarity that is currently lacking in the UK context. Detailed guidance from other contexts demonstrates how ethical, structured and well-supported engagement can be achieved in practice.

Examples include the work of Roses in the Ocean in Australia, a national organisation dedicated to supporting and embedding suicide Lived and Living Experience in prevention, policy and practice. Amongst other tools it has developed Principles of Engagement^[20], a Partnership and Integration Framework^[21], language guidance and practical safety tools. Examples from other organisations include the VocLE Delphi Guidelines^[22] which set out 96 statements addressing governance, co-design, safety and remuneration and the Youth Lived Experience Guidelines^[23] provide practical recommendations for involving young people safely and appropriately.

Together, these resources offer a strong evidence base for adaptation within the UK context.

This Fellowship explores the UK-wide context for gathering suicide lived and living experience, recognising that responsibility for suicide prevention policy and delivery is devolved across England, Scotland, Wales and Northern Ireland. While the analysis draws on learning from across the UK, the framework proposed here is set out for England, where national policy expectations are well established but practical guidance remains inconsistent. The principles underpinning this framework are intended to be adaptable within other UK nations, in line with their own governance and funding arrangements

Toward a unified framework for England

While suicide prevention policy is devolved across the UK, the analysis in this chapter highlights a particular gap in England between national policy intent and practical guidance for safely involving Lived and Living Experience.

To bridge the gap between policy intent and practice, England would benefit from a unified national framework for gathering lived and living experience of suicide. Such a framework could integrate existing policy expectations with established standards and sector expertise.

Drawing on the previously mentioned NICE and OHID guidance, NIHR INVOLVE standards, international frameworks such as those developed by Roses in the Ocean, and the expertise of organisations including NSPA, SASP and Leeds Mind, a combined model could guide partnerships through five core stages: readiness and culture; recruitment and representation; training and support; evaluation and impact; and sustainability and remuneration.

England's policy commitment to lived and living experience involvement is clear. What is needed now is a coherent, practical framework that enables this involvement to be undertaken safely, consistently and with purpose, ensuring that Lived and Living Experience is embedded as a valued and supported part of suicide prevention systems rather than dependent on individual goodwill.



Workshop discussions at the Suicide Bereavement UK Conference, informing understanding of the UK context

20 Roses in the Ocean, Principles of Engagement, 2021

21 Roses in the Ocean, Lived Experience of Suicide Partnership and Integration Framework, 2021

22 Biddle, L. et al., VocLE Delphi Guidelines, 2023

23 Webb, M. et al., Youth Lived Experience Guidelines, 2024

THEME 1

SAFETY FIRST: SUPPORTING THOSE WHO SHARE

People who share their Lived or Living Experience of suicide often do so with great emotional vulnerability. Many described being invited to share without adequate preparation, support, or follow-up put in place to keep them safe.

When organisations invite people to share their experience without thoughtful planning or care, the process can cause harm, even when intentions are good.

Creating safe and supportive environments is not optional; it is a fundamental responsibility.

Creating Safe Conditions for Sharing

Across interviews, participants described being **left feeling raw, exposed, or retraumatised after engagements where no one checked in afterwards**. Others recalled being asked to share “yet again” without knowing what their experience would be used for.

People described *feeling “used” or “left behind,”* particularly when personal contributions were treated as one-off events with no ongoing relationship or care.

Nichola Parry, Head of Lived Experience Engagement and Integration at Roses in the Ocean, emphasised that creating safe and **inclusive environments begins with transparency, clear expectations, and genuine collaboration from the outset**. She stressed that **“there’s no right or wrong way to contribute,”** but that meaningful engagement requires openness about purpose, process and boundaries.

Dr Alan Woodward, Independent Consultant, Australia, highlighted the risks of assuming that people are automatically prepared to contribute in professional or public contexts simply because they have lived experience. He stressed that **capacity-building, preparation and ongoing support are essential, so that people are not placed in unsafe or unrealistic roles**. This reinforces the principle that lived and living experience involvement must always be **underpinned by training and ongoing support**, not enthusiasm alone.

Glenda Webb, Senior Suicide Project Officer, Mental Health Network, NSW, emphasised that it is unsafe to simply “use” LLE without proper safeguards. She argued that whenever people are invited to share, organisations must consider not only the immediate impact but also the longer-term responsibility to provide support. Her challenge was clear: **“Who is looking after us?”** This underscores the principle that **ethical use of lived experience must always be paired with structures of care for all involved**.

Hayley Purdon, Founder of CriticLE, who has lived experience of suicide attempt, suicidal thoughts and caring for someone through a suicide crisis, asked the vital question: **“What is the emotional cost of sharing lived experience?”** She cautioned that participation can leave people feeling raw, unseen, or used if adequate care structures are not in place. Her insight highlights that safety is not only about the process of telling, but also about what follows, ensuring **contributors are supported, valued, and not left carrying the emotional burden alone**.

Good practice includes pacing the process, offering choice and control, and building in structured follow-up. Emotional safety also depends on relationships, being known, seen, and held with care. When done well, people said they felt valued, protected and respected. When done poorly, it left lasting damage.

The responsibility for safety sits with the organisation, not the individual. It must be embedded in the design of every engagement, not added as an afterthought. *Safety is a prerequisite for meaningful involvement, not a barrier to it.*

“I kept being asked to tell my story, again and again, and there was no follow-up, no check-in, nothing. It left me feeling exposed, not valued.”

Youth Peer Support Worker
Youth Mental Health Organisation, WA

The Value of Sharing

Despite the risks described, many participants also spoke about the deep value and meaning that can come from sharing lived and living experience when the conditions are right. Sharing can be healing and purposeful, helping some to affirm self-worth and, for others, to transform grief into contribution.

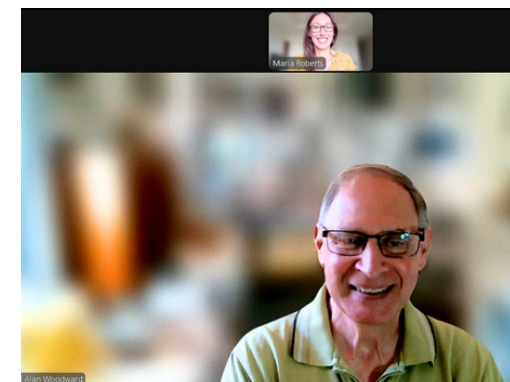
A Youth Peer Support Worker from a Youth Mental Health Organisation in WA valued **“being able to use it to actually help someone else.”**

Chris Cuttone described the agency that comes from choosing when and how to share. Zoe Strickland, author, wand maker and facilitator of creative grief circles, has found that using art and creative expression in her workshops helps to connect with others and support healing. With the right conditions, sharing can foster meaning, recovery and change.

“Some organisations require time to pass before involvement, while others make decisions case by case.” Sam Phipps

An anonymous Peer Support Coordinator, reflected: **“It’s a very long process to onboard people, and some people don’t finish it. That’s OK.”**

Dr Marianne Webb and Dr Michelle Lamblin, Senior Research Fellows at Orygen, both stressed the importance of agency. Dr Lamblin noted: **“We can create safety without taking away someone’s agency to decide when they are ready.”**



Speaking with Dr Alan Woodward on a video call

Dr Alan Woodward cautioned against paternalistic assumptions in service design, noting that **people often seek emotional support to strengthen existing resilience rather than to be ‘fixed’ by services.** Gathering lived experience with purpose therefore requires recognising and respecting the strengths people already bring.

Kristy Steenhuis, Lived Experience Development and Advocacy Lead with the StandBy Support After Suicide National Team, worked as a consultant on the film Just a Farmer,^[24] using her lived experience to review scripts, remove unsafe content and prepare cast and crew to engage safely with suicide themes. Her involvement ensured authenticity and safety, describing it as **“using my tragedy to reduce harm for others.”**

Evolving Consent and Choice

Lived and Living Experience involvement is dynamic, and consent must evolve over time.

Hope Carberry, Lived Experience Practice Lead at StandBy Support after Suicide, explained that while she once spoke publicly about both her father and brother, she now chooses not to speak about her brother's death. Her reflections show how readiness can change over time, yet the work continues to hold deep meaning:

This work gives me a reason to wake up. It's not amazing, it's PURPOSE.

Recognising changing boundaries ensures people remain in control of what they share and that their involvement remains protective rather than harmful.

What a Trauma-Informed Approach Means

A trauma-informed approach recognises that trauma may be ongoing and shapes safety needs.

Key elements include:

- Safety first: emotionally, culturally and physically safe spaces
- Choice and control: the right to choose what to share, when to be involved, pause or withdraw
- Trust and transparency: clarity about purpose and use
- Respectful communication: sensitivity to cues and tone and respecting individuality
- Follow-up and care: check-ins and continuing connection

Trauma-informed practice honours contributions while preventing harm.

Recognising the Weight of Trauma

A trauma-informed approach recognises that experiences of suicidality, grief or loss may re-emerge. Even when someone feels ready, emotions and trauma can resurface.

Ken and Lynn Barnard, who lost their son to suicide, reflected that adversity can accumulate across a lifetime, leaving older people especially vulnerable. Gathering lived and living experience must therefore prioritise patience, sensitivity and care.

Hope Carberry described unsafe events where *“the organisation assumes the speaker is safe, the speaker assumes the audience is prepared,”* including being asked whether her brother's death mirrored her father's.

These experiences illustrate why preparation, audience readiness and aftercare are essential.

Preparing to Share Safely

Preparation and training are critical to protecting both contributors and those they engage with. Chris Cuttone's experience of Roses in the Ocean training highlighted the importance of personal choice and safety^[25], sharing only what feels comfortable and withholding detail at difficult times is a strength, not a weakness. Structured training provides boundaries, skills and reassurance that contributors do not need to share everything.

Those sharing independently should still be supported by the receiving organisations to ensure they are able to make informed choices and protect their wellbeing.

“Just because someone has lived experience doesn't mean they know how to hold space for others. I wasn't trained, and I didn't realise how much it could impact me until afterwards.” Interview participant

Lived experience offers deep empathy, but facilitating others requires skill, supervision and organisational support.

Protecting Communities from Media Harm

Media projects can amplify harm if they are rushed or handled without care. Several participants reflected on projects that approached individuals and families too soon after a suicide, without adequate preparation or safeguarding.

Kristy Steenhuis challenged unsafe film and media projects that engaged bereaved families prematurely, approaching families in the days following a suicide, without consideration of the trauma involved.

warning that communities must not be treated as “click-bait.” She emphasised the responsibility of organisations to prioritise care over urgency.

Everymind’s Media Guidelines for Reporting Suicide^[26] outline principles for safe and responsible reporting. However, participants stressed that guidelines alone are not sufficient. **Genuine partnership with lived experience contributors and bereavement organisations is essential to prevent exploitation and further harm.**

What Does Safety Mean?

Safety means contributors feel secure to share without fear of harm or exploitation. It includes:

- Clarity: clear purpose and use of contributions
- Boundaries: knowing what will and won’t be asked
- Support: check-ins, aftercare, referral pathways
- Environment: inclusive, respectful spaces
- Consistency: keeping promises and follow-through

When people feel safe, they can share openly and meaningfully.



With Dr Anat Wilson during fieldwork in Australia

The Power of a Clear Question

Dr Anat Wilson, Research Manager at a global charity organisation, reflected on the limits of empathy alone in suicide prevention work. She observed:

“No amount of empathy or sharing my lived experience was as powerful as asking the question: Are you having thoughts of suicide?”

Her reflection highlights that while empathy builds trust, asking direct and clear questions can open honest dialogue and create pathways to support when risk is present.

Voice of Lived Experience: Stephen Rothwell

Stephen Rothwell, Advocate, Writer and Educator, who has shared his Lived and Living Experience in many settings, described one engagement that felt “magic,” where care, time and mutual respect were present.

In contrast, he reflected on other occasions where he felt “used” or “rushed,” with no follow-up after sharing deeply personal experiences.

His reflections underline the difference between sharing experience as a genuine human connection and being asked to re-live pain in ways that feel extractive.

Stephen is a suicide survivor who now campaigns for suffering reduction and suicide prevention. He is deeply involved in developing trauma-reduction resources, including workbooks, courses, articles and illustrations.

Steve’s Lived Experience includes encounters with carceral and mental health systems, but his story is far more than what happened to him, it’s about what he’s done with it.

His workbook, *Breaking Free from ‘Stuck Points’*, invites others to identify harmful internal narratives and reframe them into future-oriented beliefs.



With Stephen Rothwell at the Roses in the Ocean Summit, Brisbane, March 2025

“There’s a difference between being heard and being used. I’m not here for your report. I’m here to make a difference.”

***“I told my story again and again.
No one ever told me what happened with it.
Did it make a difference?
Or was it just another ticked box?”***

Lived Experience Advocate, Australia

THEME 2

MORE THAN A STORY: PURPOSEFUL PRACTICE

Lived and Living Experience is not a resource to extract. It is a person's truth. Across interviews, participants described being asked to share deeply personal experiences without clarity about why they were being asked or how their contribution would be used. When purpose is unclear, lived experience can be reduced to performance or box-ticking, rather than recognised as expertise.

THE JOURNEY OF INVOLVEMENT

BEFORE

- Right people, right role
- Clear purpose
- Informed consent
- Preparation and support

DURING

- Shared power
- Skilled facilitation
- Emotional safety
- Clear boundaries

AFTER

- Follow-up and support
- Feedback and communication
- Demonstrating impact
- Ongoing connection

Reflects themes identified through workshop discussions at the Suicide Bereavement UK Conference (2025)

Clarity and Purpose

Purpose is the foundation of ethical involvement. When it is absent, involvement can feel extractive rather than collaborative. True co-production begins early, shaping questions and priorities rather than responding to decisions that have already been made. Clear purpose protects against surface-level involvement and ensures that lived and living experience is used to drive meaningful change.

Being explicit about why lived and living experience is being sought, what influence it will have, and what outcomes are possible allows people to decide whether and how they want to be involved.

Transparency and Feedback Loops

Transparency builds trust. Contributors consistently described the importance of knowing how their input would be used, what decisions followed, and whether their contribution made a difference. Without feedback, lived experience can feel as though it disappears into a void.

Glenda Webb emphasised the need for protective structures, including transparency within ethics applications, recognising the emotional impact of involvement and ensuring support is in place. For her, transparency means showing people clearly where and how their voices influenced change.

Closing the feedback loop is not an optional extra. It is a core part of ethical practice.

Organisational Readiness

Readiness goes far beyond inviting people into a room. It includes organisational culture, structures, and resources that enable meaningful involvement. Being explicit about purpose, scope of influence, and available support allows people to make informed choices about participation.

Moving progressively from consultation to co-design, co-production, and lived-experience-led work requires trust and shared decision-making at each stage. When work is labelled as co-production but does not genuinely share power, trust is damaged.

“Be honest about what is actually co-produced and what isn’t. People respect clarity. What causes harm is being told they have influence when decisions are already made.”

Dr Alan Woodward, Independent Consultant, Australia

If organisations aren’t honest about the scope of influence, people quickly see through it. It damages trust and risks tokenism.”

Dr Lennart Reifels, Senior Research Fellow The University of Melbourne

Honesty about limits does not weaken involvement. It strengthens it by allowing people to choose how they engage.

Resourcing and Funding

How involvement is resourced reflects how it is valued. Many participants described being asked to contribute their time, expertise, and emotional labour without compensation, while consultants or professionals were paid.

“They wanted my time, my experience, and my pain for free. But the consultants got paid.”

Peer Advocate, Australia

Meaningful involvement requires funding for briefing, support, debriefing, and fair compensation for time and expertise.

Without adequate resourcing, lived and living experience involvement risks placing disproportionate emotional and practical demands on contributors.

Governance and Structures

When involvement is labelled as co-production but real influence is limited, trust is damaged.

At Lifeline Australia, an Oversight Group with LLE representation contributes from design through to delivery.

“The Oversight Group means lived experience is part of every step, from the design stage through to delivery.”

Dr Anna Brooks, Chief Research Officer, Lifeline Australia

Governance structures such as these ensure lived experience is not an add-on, but a consistent presence shaping decisions over time.

MENTAL HEALTH FIRST AID INTERNATIONAL

Building Purpose into Program Design

At Mental Health First Aid International, Lived and Living Experience is embedded across course design, delivery, and evaluation.

Personal experience is included with clear intent, linked directly to learning objectives rather than shared for its own sake.

Briefing, training, and debriefing processes are built into each stage to maintain safety and meaning.

Lived experience also informs evaluation and quality improvement, shaping how training effectiveness is measured and strengthened over time.



Mental Health First Aid International Headquarters, Melbourne

“We try to avoid the ‘tell your story’ model unless it’s directly tied to a learning objective. When we do include it, we ensure it’s framed, purposeful, and safe.”

Marc Bryant, Executive Director, Mental Health First Aid International

ROSES IN THE OCEAN

Embedding Purpose and Integrity



Roses in the Ocean Head Office, Brisbane, Displaying Meaningful Pieces

Roses in the Ocean begins with clarity. Why Lived and Living Experience is sought, who is best placed to contribute, how it will be used, and who benefits are all considered before engagement begins. Matching people to projects takes account of readiness, culture, and safety.

The Partnership and Integration Framework^[27] supports both contributors and organisations through preparation, briefing, debriefing, and skills development, alongside readiness training for organisations.

“Organisations must be clear as to why they are engaging people with lived experience and ensure they allocate the appropriate time and resources to integrate and partner meaningfully. If you don't know why or don't value the expertise lived experience can bring, don't do it tokenistically. Get clear first, then invite people in.”

Bronwen Edwards, CEO, Roses in the Ocean

“We've built engagement models where people can see the loop. What happened, who listened, what changed. That's the minimum standard, not the gold one.”

Nichola Parry, Head of Lived Experience Engagement and Integration, Roses in the Ocean

THEME 3

RETHINKING THE WORKFORCE: WORKING WHILE HEALING

Australia has developed a growing workforce of Suicide Peer Workers, people employed for the value of their suicide-related Lived and Living Experience. These roles are embedded across services, research, leadership and community settings. No comparable structure exists within UK statutory systems, making this a key area for learning. When supported through training, supervision and cultures of care, lived and living experience becomes professional expertise.

Healing following suicidal distress or bereavement is not a fixed endpoint.

Contributors challenged the assumption that people must be “fully healed” before working safely in suicide prevention roles.

Within supportive environments, lived and living experience is ongoing and evolving. Rather than limiting contribution, this proximity can strengthen empathy, credibility and connection.

A Youth Peer Support Worker in Western Australia reflected: **“Sometimes you have to pull back to refill your cup. You can’t pour from empty.”**

This highlights that sustainability depends not on distance from experience, but on boundaries and support.

A Peer Support Coordinator observed that colleagues can feel uncertain: **“People are fearful and walking on eggshells. They don’t want to get it wrong.”**

This reinforces the importance of organisational readiness, not individual resilience alone.

Defining the role

In Australia, a Suicide Peer Worker draws on direct experience of personal suicidality, supporting someone else, or bereavement to offer genuine human connection. Their expertise lies in empathy and shared understanding rather than diagnosis.

They work across a range of settings, supporting people in crisis, co-facilitating groups, contributing to research, and shaping services, policy and training.

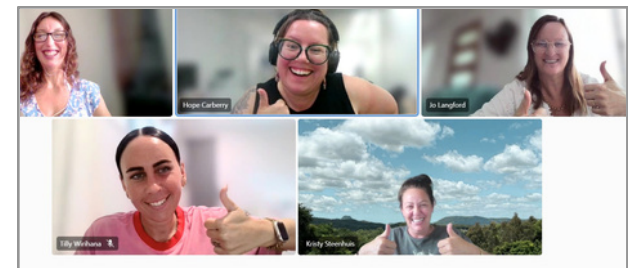
Lived and Living Experience is recognised as expertise, not something to perform. Workers choose when and how to draw on it, with clear boundaries to protect their wellbeing.

These roles are supported through training, reflective supervision and strong team cultures, ensuring experience is held safely within the organisation.

StandBy Support After Suicide has embedded lived and living experience across national leadership.

The Lived Experience National Team, led by Jo Langford, is made up entirely of people with lived and living experience of suicide and helps shape service delivery, workforce development and national strategy.

This shows how LLE can be embedded not only in frontline roles, but across systems and decision-making.



With the Lived Experience National Team, StandBy Support After Suicide

Team culture and training

Supportive teams thrive when clinical and professional colleagues value lived experience as an equal form of expertise. Suicide Peer Workers then feel respected and integral to the team.

Yet, as Sam Phipps, observed:

“We often see a high turnover of staff within the Lived Experience Peer Workforce when the organisational readiness, culture, and systems that they are working within are not set up to support them.”

Organisational readiness training reinforces a collective care culture. Induction covers boundaries, trauma-informed care, and response to suicidal crisis and emotional distress, while group co-reflection and communities of practice sustain confidence and connection.

Managers and clinicians also receive training, so Suicide Peer Workforce roles are recognised as skilled and equal within the workforce.

As one contributor summarised:

“Training makes the role real.”

Sustaining the workforce

When workplaces are designed to support the suicide peer workforce, roles can be sustained safely over time. Insight, compassion, and credibility drawn from lived and living experience can strengthen teams and services when this workforce is respected and properly supported.

Professionalisation remains an active and evolving discussion in Australia. As the suicide peer workforce has become more established, questions continue to be explored about how best to balance safety, recognition, inclusion, and accessibility.

These discussions include the role of formal qualifications, workforce capability frameworks, and minimum standards, alongside a strong emphasis on ensuring that lived and living experience remains central rather than marginalised.

Formal qualifications are one part of this conversation. While they may offer consistency and recognition for some roles, there is broad recognition that they should not replace lived and living experience as the core source of expertise.



With Glenn Cotter at the Roses in the Ocean Summit

As Glenn Cotter, Lived Experience Peer Worker and Advocate, Healthy Communities Foundation Australia, said:

“I don’t have formal qualifications. My qualification IS my lived experience.”

National initiatives such as the Australian Government's Lived Experience (Peer) Workforce Capability Framework^[28] and the WA Mental Health Commission's workforce project^[29] reflect this ongoing dialogue.

These initiatives are being developed through consultation and aim to embed minimum safety standards, supervision, equitable pay, and clearer career pathways, while continuing to engage people with suicide-related Lived and Living experience in shaping the future of the workforce.

Sustainability is also shaped by personal context and the conditions people work within. Suicide Peer Workers bring their whole selves to the role, and pressures outside work can influence wellbeing and capacity.

People do not need to be fully healed to contribute safely and skilfully.

When supported by clear boundaries and reflective supervision, Lived and Living experience of suicide becomes professional expertise.



With Glenda Webb in Liverpool City Centre, New South Wales

As Glenda Webb reflected:

“When the systems around you aren’t supportive, you start to break down in other areas of your life.”

To sustain this workforce, organisations need to provide fair pay, secure contracts, and flexible pathways that allow people to step back or change roles without stigma.

External supervision, reflective spaces, and access to wellbeing supports are essential. Applying an intersectional lens that considers race, age, gender, culture, sexuality, disability, neurodiversity, and socio-economic background, helps ensure every Suicide Peer Worker feels safe, valued, and included.

Embedding Lived and Living Experience across all levels

While suicide peer work is most visible on the frontline, contributors consistently stressed that Lived and Living Experience must also shape governance, policy, research, and leadership.

Chris Cuttone, Wesley Mission and Co-Chair, PaRK Collaborative, stated:

“We need to embed lived experience across all levels, not just in peer roles.”

Bronwen Edwards, CEO at Roses in the Ocean, observed that executive and board-level representation of lived and living experience remains limited.

Dr Lennart Reifels, Senior Research Fellow at The University of Melbourne, highlighted that research partnerships are often consultative rather than collaborative, noting efforts within his team to position people with lived and living experience as genuine co-investigators.

Embedding suicide-related Lived and Living Experience across systems leadership helps normalise authenticity, challenge stigma, and ensure decisions are grounded in the realities of suicide experience.

28 Australian Government, National Lived Experience (Peer) Workforce Capability Framework, 2023

29 Government of Western Australia, Mental Health Commission, Lived Experience Workforce Project, 2022



Melbourne City Centre, Australia

Valuing the Role

Valuing Suicide Peer Workers means designing systems that hold both humanity and skill.

Creating trust-based teams, equitable pay, clear scope, external supervision, reflective spaces, flexible pathways, and leadership opportunities beyond frontline roles.

With these conditions, people can, and do, work while healing. The result is stronger connection, safer practice, and better outcomes for the communities served.

“Sometimes you’ll phone another peer worker and say that was particularly tough, ...we picked each other up.”

Suicide Peer Worker, Australia

Voice of Lived and Living Experience: Olivia Centaine

Olivia Centaine is a Suicide Peer Support Worker within an Early Psychosis Program, Western Australia.

Olivia is a mother. The birth of her daughter marked a turning point in how she understood herself and her future. Diagnosed with Autism Spectrum Disorder in childhood and later with ADHD in early adulthood, gaining clarity about her neurodivergence helped her make sense of earlier struggles.

Her professional role is grounded in her own lived and living experience of suicidality, self-harm and addiction.

“It’s not that I wanted to harm myself... it’s that I simply didn’t want to exist in a world with this much pain.”

Her final suicide attempt, ten years ago, required emergency medical intervention. Yet she rejects the idea that recovery is a closed chapter.

Today, Olivia supports young people experiencing early psychosis. She is clear about boundaries. She is not a clinician and does not provide medical advice. Her contribution is relational.

“I know what it’s like to walk through the doors of a mental health service.”

Her workplace explicitly values lived and living experience within recruitment. She described feeling able to speak openly in her interview when told her experience would be seen as an asset rather than a risk. Her role is supported by structured training and supervision.

“In some sessions we don’t share any of our lived experience.”

For Olivia, suicide peer work is not about being fully healed.

“It’s about showing that you can live with it, move forward, and build a life that isn’t just about surviving, but truly living.”

She connects this to her belief in “The Dash” The space between birth and death, where we live and find meaning.

Olivia’s experience demonstrates that with training, supervision and organisational clarity, Lived and Living experience becomes expertise. It strengthens engagement, reduces power imbalance and offers credible hope.



Olivia Centaine at the Early Psychosis Centre, WA, Australia

“I don’t believe ‘lived experience’ is the right term... we are still living in it, growing through it.”

“The cause of suicidal distress and crisis is not always a mental health challenge or illness, with situational distress often leading people to experience contemplating ending their life.

So the suicide prevention peer workforce must be representative of the wide range of intersecting experiences of suicide, and the unique needs of people.”

Bronwen Edwards, CEO, Roses in the Ocean

THEME 4

SHARING POWER: INCLUSION TO PARTNERSHIP

This theme focuses on power, influence and shared leadership across systems. It explores whether Lived and Living experience is merely invited into spaces, or whether it holds genuine authority to shape decisions in policy, research, governance and service design.

The Journey of Involvement

Inclusion without influence risks reproducing existing hierarchies rather than transforming them.

Across interviews, many people with Lived and Living Experience of suicide described being invited into systems **but not truly heard**. Their involvement often stopped at consultation or feedback, rather than extending into genuine partnership or shared decision-making.

Nichola Parry, Head of Lived Experience Engagement and Integration, Roses in the Ocean (Brisbane), reflected:

“We’re still in a system that values professional qualifications over lived experience. So even when we’re co-designing, the power still sits with the organisation.”



Online call with Emma Elder, Blackdog Institute (NSW)

Emma Elder, Lived Experience Program Manager, Black Dog Institute (New South Wales), echoed this sentiment:

“Power-sharing doesn’t mean giving something up. It means creating space for different types of knowledge to shape the work.”

True partnership requires more than presence. It involves shared control, responsibility and trust.

Stephen Rothwell, Advocate, Writer and Educator, described how authentic relationships shift influence:

“When you build a real relationship, it’s not about a one-off project. It’s about walking alongside each other. That’s where trust starts and where change starts too.”

Trust takes time and is built through consistent behaviour.

Kristy Steenhuis, Lived Experience Advocacy and Development Lead, StandBy Support After Suicide, explained:

“Shared leadership only works when people know they’re safe to say the hard things, not just the nice things.”

Hayley Purdon, Founder of CriticLE, added that people living with suicidality often hold the clearest insight into systemic failings, yet may be excluded for being perceived as “unsafe” voices.



Taking a walk on Bondi Beach, Sydney, with Hayley Purdon

Hayley Purdon, Founder of CriticLE, commented that *“people living with suicidality often hold the clearest insight into systemic failings, yet may be excluded for being perceived as ‘unsafe’ voices.”*

Talking about the centrality of trust:

“You can’t expect someone to share openly if the system hasn’t shown them that it’s safe. Trust is earned over time, not just given because you’ve invited them into a room.”

Recruitment and Pathways

Recruitment is one of the most visible expressions of power-sharing. How roles are designed, who is invited to apply, and how selection decisions are communicated all signal whose expertise is valued.

At an Early Psychosis Program, in Western Australia, structured recruitment processes support the safe integration of people with suicide LLE into multidisciplinary teams. Job descriptions list lived experience as an asset, and supervision and training are built in to support sustainability.



At the Black Dog Institute office, Sydney

At the Black Dog Institute, Emma Elder and Hayley Purdon use a **formal expression-of-interest process to match contributors to projects**. This approach **increases transparency and clarity** but can also create disappointment when people are not selected.

Emma and Hayley, both agreed that *“Selective recruitment can create unintended harm if not managed carefully. People may feel their experience is less valid if they’re not chosen, adding to their distress.”*

Clear communication, feedback and alternative pathways for involvement help reduce feelings of exclusion or judgement. At Black Dog Institute a wide range of roles and opportunities are made available to ensure there are multiple meaningful ways to contribute.



City View of Melbourne

With Dr Reifels at University of Melbourne

In research contexts, Dr Lennart Reifels, University of Melbourne, uses the Delphi method to place academic and lived expertise on equal footing:

“The Delphi method allows us to hear from both researchers and people with lived experience, to find consensus around priorities and ethical involvement.”

Ethical recruitment therefore involves explicit invitations to suicide LLE, transparent selection processes, feedback for those not chosen, emotional safety, role clarity and fair remuneration.

Evolving Expectations of Lived and Living Experience

Across Australia, expectations of lived and living experience involvement have shifted significantly. Contributions have moved beyond personal sharing toward shaping systems, research, governance and innovation.

Bronwen Edwards, CEO of Roses in the Ocean, explained:

“The role of people with Lived and Living Experience of suicide has evolved significantly over the last 10 years from only being engaged to share experiences to shaping service design, system reform, research and leading innovative community initiatives.”



Video call with Dr Woodward

Dr Alan Woodward noted:

“Building influence requires more than presence. It requires preparation, structure and a clear invitation to participate meaningfully in design, strategy or governance.”

Chris Cuttone, Wesley Mission and Co-Chair of the PaRK Collaborative (WA), emphasised dignity and agency:

“We talk a lot about inclusion, but what about dignity, about giving people the agency to lead something from the start, not just rubber-stamp it at the end?”

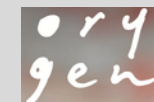
Examples of progress in Australia:



A Roses in the Ocean’s Future Leaders Program^[30] aim to develop diverse lived experience leadership and ensure sustainability within the movement.



Lifeline Australia, where governance advisory groups are co-led by people with LLE guide service design and research



Orygen, which provides pathways from consultation to co-production and employment, blending lived and professional expertise



With Ken and Lynn Barnard in their home, South Sydney

Ken Barnard, Bereaved Parent and Lived and Living Experience Volunteer, reflected:

“Sometimes you speak up and it just lands flat. Like they’ve ticked the box but they’re not actually listening. You start to feel like your role is to keep fighting, not contributing.”

These reflections show that progress depends not only on frameworks and policies, but on everyday behaviour, listening, responding and acting on what people share.



With the Northern Star Suicide Prevention Network

Sharing power and leadership in practice

During fieldwork in Western Australia, I presented my Churchill Fellowship to two collaborative networks: the Northern Star Suicide Prevention Network and the PaRK Collaborative. These spaces bring together organisations, practitioners, and people with lived and living experience across suicide prevention.

They are collaborative forums where learning and insight are shared openly across organisational boundaries. People contribute as equals, with lived and professional expertise sitting side by side, often both.

The level of collaboration is notable. Organisations learn from one another, share responsibility, and shape approaches together. Lived and living experience is embedded within collective decision-making.

These networks demonstrate how shared leadership works in practice, creating space for dialogue, building trust, and enabling LLE of suicide to influence systems.

Principles for Shared Leadership

- Value multiple forms of expertise
- Build trust through long-term relationships
- Embed lived and living experience in governance and recruitment
- Resource and pay people fairly
- Measure influence, not attendance



With the PaRK Suicide Prevention Collaborative, WA



Speaking at the Northern Star and the PaRK Collaborative Suicide Prevention Networks

Voice of Lived and Living Experience: Dr Tara Lal

Dr Tara Lal lost her brother to suicide and is a qualitative researcher, former firefighter and author of *Standing on My Brother's Shoulders: Making Peace with Grief and Suicide*.

Dr Lal described the line between being valued and being reduced to a single perspective:

“Sometimes it felt like my Lived and Living Experience was just being used for someone else’s agenda. With Beyond Blue I was included with clarity and purpose. I knew why my experience was being asked for.”

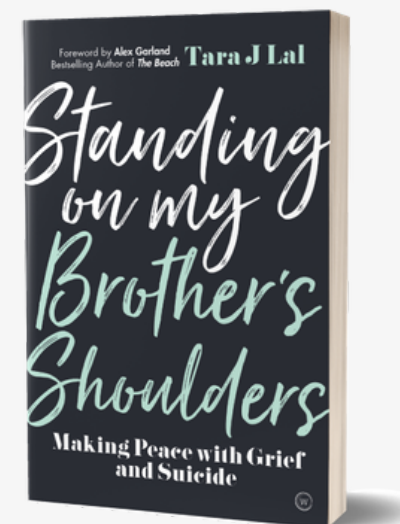
Her professional exposure compounded personal loss:

“I was holding the weight of my own experience, while also being faced with suicide in my work. You can’t always separate the personal from the professional in this space, and nor should you have to.”

Through her PhD, she reframed suicide bereavement as trauma:

“I came to understand that suicide is trauma, not just grief. That recognition changes how we listen, how we respond, and how we support.”

Tara’s reflections underscore the importance of transparency, shared purpose and recognition of emotional labour as the foundation of trust and ethical collaboration.



THEME 5

WORDS SHAPE WORLDS: LANGUAGE AND NARRATIVE

Language is never neutral. In suicide prevention and postvention, words shape whether people feel safe to speak, how they are understood, and how services respond. Language can invite dignity and trust, or reinforce stigma and silence.

Several contributors emphasised that language is inseparable from power. The dominant terms used in research, policy, services, and media either entrench hierarchies or make space for new voices. Language shapes how professionals relate to people in distress, how systems respond, and what is considered acceptable to say publicly.

Tara Lal captured this clearly:

“When I hear the phrase ‘commit suicide’, it jars every time. That language carries history, of crime, of judgement. It tells people their pain is something shameful.”

This theme explores how lived and living experience is reshaping language across research, media, services, and training, supporting dignity, agency, and meaningful change.

Language in research and policy

Language shapes how suicide is understood, funded, and addressed. In research and policy, the words chosen can either challenge stigma or reinforce it. They influence which experiences are prioritised, how risk is framed, and how responses are shaped.

Associate Professor Jacinta Hawgood, Program Director Suicidology and Clinical Psychologist, Australian Institute for Suicide Research and Prevention, Griffith University, described the concept of *lived proximity* - understanding is developed through long-term work and building of social relationships alongside affected people: **“Every millimetre of learning matters. Every voice adds richness.”**

Naming the Experience, Not the Person

Labels can dehumanise. Sam Phipps, explained: **“People are not their crisis. If we want people to open up, we have to stop reducing them to a diagnosis or an event. Language shapes what’s possible.”**

This reframes suicide as an experience, not an identity, helping reduce stigma and improve connection.



With Dr Lamblin at Orygen Centre, Parkville, Melbourne

Dr Marianne Webb, Senior Research Fellow, Orygen, reflected:

“Language in research has implications. If we keep referring to certain groups as ‘high risk’ without context, we reinforce stereotypes and leave little room for strength-based narratives.”

Together with Michelle Lamblin, she co-produced a youth-informed language framework to promote safer and more inclusive research and service design.

Orygen has developed youth-informed language guidance^[31] which now informs national research, training, and communications, showing how co-produced language guidance can shift systems.

Language in media and public narrative

The influence of language extends beyond research and policy into media representation and public reporting. Media narratives can either humanise people and their experiences or focus narrowly on crisis in ways that overlook the fullness of a person's life.

When reporting makes judgements, assumptions, or misrepresents people's lives, it can distort public understanding and cause further pain for those bereaved and impacted. Some coverage still fails to follow media guidelines, using language that blames, sensationalises, or reduces a person's life to the circumstances of their death.

Families often push back against portrayals that overlook the fullness of a person's life.

“That’s just a bookend; it’s a very small percentage of their life.”

Hope Carberry



Kristy Steenhuis at Standby Support After Suicide

Kristy Steenhuis, StandBy Support After Suicide, advocates for co-designed, responsible sharing of Lived and Living Experience, ensuring contributions are handled with care.

Language in services

The language used within support settings is as influential as the words chosen in media or policy. It shapes relationships, conveys respect, and signals the nature of partnership between people and services. It also influences how people are perceived, labelled, and supported, and how care is experienced.

Across interviews in Australia, many suicide prevention and support services described referring to the people they support as *clients* or *guests*. This reflects an approach in which people are recognised as entitled to care and support with dignity and choice. In the UK, the term *service user* remains more common, with some use of *guest* in peer-led services. These differences highlight how language reflects national culture, service design, and power dynamics within support and care settings.

Jimmy Morrison, Medicare Mental Health Centre, Penrith described how subtle shifts in language can change relationships and expectations:

“We call people guests. We talk about discomfort agreements, not safety agreements, because growth often involves discomfort.”

This approach reflects trauma-informed practice, where language is relational rather than transactional. Words are chosen deliberately to honour autonomy, reduce hierarchy, and acknowledge that healing can feel uncomfortable while remaining grounded in safety and trust.



A welcoming space for conversations at Medicare MH Centre, Penrith

Guy Mazzella, a Volunteer Digital Crisis Support Worker at Lifeline Australia, reflected on the challenges of communicating through text-based crisis support, where there are no verbal cues to guide the interaction. He described using short reassuring phrases such as **“I’m here”** and **“I’m listening,”** alongside rapid responses, to help people feel heard and supported during moments of distress.

Training professionals on language

Professionals who work with people with LLE are not always trained in relational or trauma-informed language, even though it is central to building trust.

Associate Professor Jacinta Hawgood observed: ***“We spend years training professionals on procedures and suicide assessment processes, but not huge emphasis on safe and appropriate language - especially in therapeutic settings. Words matter. They can build trust and ongoing engagement (earlier too) or create distance.”***

Stephen Rothwell also commented: ***“Are you ok?’ is a shutdown question. We need emotionally literate alternatives like, ‘I think you may have some things you need to talk about, I am here to listen’, words that open a door, not close it.”***

Jimmy Morrison reinforced this point: ***“Language shapes the relationship. When we change words, we change the space people step into.”***

However, contributors also cautioned that overly rigid control of language can create barriers, particularly when fear of getting the wording wrong prevents people from having open, human conversations.

Suicide Prevention Coordinators at Neami National Perth, explained: ***“The extreme management of language can stop people from talking freely.”***



With Dr Anna Brooks, Chief Research Officer, Lifeline Australia

Dr Anna Brooks, Chief Research Officer, Lifeline Australia, emphasised that language must be tested with communities to ensure it feels authentic and inclusive:

“Language has to be tested with communities, otherwise you risk alienating the very people you are trying to include.”

Language training should therefore prioritise relational skill, using words that invite, connect, and demonstrate respect and care.

When Language Misrepresents

Many people who experience suicidality have no mental health diagnosis. Suicide is often framed primarily as a mental health issue, yet this can be misleading. A narrow illness-focused frame risks overlooking social, relational, and structural drivers of distress. Using mental health language inappropriately can create misconceptions about the nature of suicidal distress.

Dr Lennart Reifels, University of Melbourne warned:

“There’s a real risk in equating suicide solely with mental illness. It can mean people who are bereaved, in crisis, or facing social adversity are overlooked because they don’t fit the model.”

Language should name distress linked to trauma, loss, physical health, or social determinants, rather than labelling a person or placing them in an inappropriate box.

Roses in the Ocean: Leading the Language Conversation

Roses in the Ocean’s Lived Experience of Suicide Language and Imagery Guide^[34] offers practical, respectful recommendations, now used by government, clinical teams, educators, and researchers. The guide has influenced policy, funding, protocols, and media practice throughout Australia.

THEME 6

CONTEXT MATTERS: IDENTITY, CULTURE, COMMUNITY

Gathering Lived and Living Experience of suicide cannot be separated from the cultural, historical, and social contexts in which people live. Culture shapes how difficult experiences and loss are expressed, how grief is carried, and whether people feel safe to speak or share their experiences.

Throughout this Fellowship, contributors described culture broadly, reflecting their own contexts and experiences. This included discussions of ethnicity, heritage, faith, sexuality, gender identity, disability, neurodivergence, class, and language, though this is not an exhaustive list. These intersecting identities influence how suicide is talked about, where help is sought, and how people engage with services.

At its core, safety is cultural. **For people to feel safe sharing lived and living experience, their identity must first be respected.**



Melbourne Street Art, 2025

Culture Shapes Safety

People do not all talk about suicide in the same way. Words, expressions, and silences carry different meanings depending on cultural background, community norms, and personal history.

Sam Phipps commented:

“We don’t all talk about suicide in the same way. Even the word itself can feel uncomfortable or not fit with how someone thinks or feels, and their cultural environment.”

Barriers include shame, family reputation, or fear of disbelief. Along with wider trauma from racism, colonisation, gender-based violence or mis-treatment, or exclusion that erodes trust in services.

Creating culturally informed conversations means letting people define their own terms and pace. In practice, this can involve working with LGBTQIA+ networks, interpreters, or cultural liaison staff.

Gathering LLE should never be one-size-fits-all. It must adapt to who is present and what supports people to feel seen, safe and understood.

*“I experienced the loss of two beautiful men...
but I learnt that I had to
‘be quiet’ about my father’s death.
It was very hard for me to say
the ‘S’ word.”*

Systemic inclusion and missing voices

A culturally informed approach also requires attention to systemic inequities that shape whose voices are heard and whose are overlooked.

Associate Professor Jacinta Hawgood, Griffith University, commented: *“When we talk about Lived and Living Experience, we also have to consider whose voices are missing, culturally, geographically, systemically.”*

She noted that we can still stand back and observe that frequently leadership in suicide prevention often defaults to those already in positions of status or power. Real inclusion demands long-term partnership or collaborations and inclusion of those with LLE, not just one-off gestures.

Professor Kairi Kólves, Griffith University, also said: **“There is no universal way of understanding or responding to suicide. Culture, gender, migration status, all of these things [and many others] influence both the experience and the recovery process. We need to be careful not to impose a Western lens on everything.”**

Both emphasised that **culturally and linguistically diverse communities (CALD) must be equal partners in research, service design, and governance.**

“Am I Safe Here?”

A question at the heart of sharing lived and living experience

Chris Cuttone, Peer Worker and Co-Chair of the PaRK Collaborative* explained how safety and identity shape disclosure:

“I choose to use the term Queer because I am non-binary and this is how I choose to identify. Sometimes I just say, ‘I have lived experience of suicide’ and nothing more. If I feel safe in that space, I’ll expand. If I’m not safe as a queer person in that environment, I won’t share my lived experience.”

This highlights that people constantly assess whether a space feels safe before deciding how much of themselves to bring into it.

* A shared space where organisations, practitioners, and people with lived and living experience come together to exchange knowledge, shape practice, and influence suicide prevention and recovery efforts across Western Australia.

LIVERPOOL SAFE HAVEN: A PEER-LED MODEL SHAPED BY COMMUNITY CONTEXT

Liverpool Safe Haven provides a peer led, non clinical space for people experiencing suicide distress. Located in a culturally diverse area of south west Sydney, the service was designed with cultural and linguistic inclusion at its core.

The model is fully peer led, with all staff, including the Manager, bringing Lived and Living Experience. This shapes how support is offered, grounded in trust and shared understanding.

Glenda Webb, Service Manager, explained:

“We have an incredibly diverse population. People need to feel safe and understood. Sometimes that means having someone who speaks their language, or who understands where they’re coming from.”

Rather than escalating risk or defaulting to hospital pathways, Peer Workers respond with calm, openness, and choice.

“It’s about building trust and offering choice. Some just want to sit with someone who gets it.”

People can attend at any stage of distress, with no appointments and no limit on visits.

Context shapes the design of this service, from who delivers it to how support is offered and how risk is understood.



Safe Haven sign at the main entrance

Creative Connection: Expression within identity and community

For many people, traditional verbal consultations are not the safest or most natural way to share. Creative expression, including art, cooking, weaving, music, and other embodied practices, can offer alternative ways to connect, process, and communicate lived and living experience.

Expression is shaped by identity, culture, language, and community. For some, meaning is not easily communicated through conversation, but through creating or being alongside others. These approaches can support connection without the need to explain or translate experience into words.

In many settings, gathering Lived and Living Experience is centred on interviews, speaking at events, or contributing to boards. While valuable, these approaches may not reflect how people feel safest expressing themselves, particularly where trust is still being built or where experiences are difficult to articulate.

Creative approaches can reduce pressure and allow individuals to engage at their own pace. They create shared spaces where people are side by side rather than face to face, shifting the dynamic from being asked to explain, to being invited to participate.

When thoughtfully facilitated, these approaches support the gathering of Lived and Living Experience in ways that are more inclusive, culturally responsive, and grounded in trust.

VOICE OF EXPERIENCE: *Cooking as Care*

Chaya Vogelpoel-Rainbird, described how food and cooking became central to her way of expressing and supporting others.

“We can intentionally cook for the bereaved to help them know we are there. Food is a universal language.”

Cooking became a tangible way to show care to bereaved children and families.

“I used food and flavours to trigger memories and feelings....to help the children in my foster care to anchor safely with memories, so that they can remember the people from the past.”

Media and creative practice

Kristy Steenhuis, Lived Experience Development and Advocacy Lead at StandBy Support After Suicide, described media as a powerful form of expression when used with care.

Kristy provided lived experience advice on the feature film *Just a Farmer*, educating the production crew, advising on unsafe content, and supporting cast and crew. This resulted in a film that portrayed farming communities and suicide bereavement in a way that prioritised safety, dignity, and community wellbeing.

Kristy also used her advisory role to prevent unsafe media projects, advocating against the production of a film, by a different company, depicting multiple youth suicides based on real events, recognising the potential harm to individuals and communities.

CREATIVE CONNECTION, EXPRESSION BEYOND WORDS

For many people, traditional verbal consultations and engagements are not the safest way to share. Creative expression, including art, cooking, weaving, music, and other embodied practices, can offer alternative ways to connect, process, and communicate Lived and Living experience.

Zoe Strickland, author, wand maker, and facilitator of creative grief circles, shared how creativity supported her own bereavement.

As a bereaved mother and creative advocate, Zoe used journaling and her sketch persona, Doodle Lady, to process and express grief.

Several years later, a compilation of her diary entries and doodles were published as *To Grief With Love*,^[35] a lyrical and pictorial voyage through loss. In early grief, Zoe intuitively turned to creative pursuits, including wand making, initially for herself and later as gifts for others. She later hosted grief circles centred on wand making, blended with intention setting and gentle meditation.

Zoe reflected that in creative circles, people are often side by side rather than face-to-face, allowing conversation to unfold gently without pressure or formal direction. The sharing was not intense, but softly held, grounded in mutual understanding, metaphor, and hope.



Courtesy of zoestricklandpublishing.com



With Zoe Strickland, Sunshine Coast, 2025

WEAVING THROUGH LOSS

Raven Spirit, who has multiple suicide losses including his brother and his father and a friend, spoke about the strength of creative approaches when loss from suicide makes verbal communication challenging. He has explored fibre weaving as a way of processing and integrating suicide loss, both for himself and within community settings.

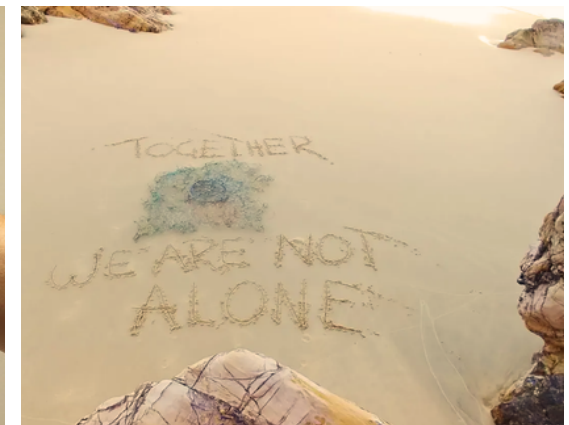
Reflecting on this process, he writes on the *Renewed Spirit* website: ^[36]

“Weaving with natural fibres became a major tool for me to hold on whilst I cycled through the endless cycles of suicide bereavement.”

“Initially weaving was purely something I did whilst my mind was overcome with the intensity of the thoughts, feelings and relentless incomprehensible cycles of losing my brother by suicide... a way in which I could somewhat anchor myself...it allowed me to sit with the memories. As time went by, the entire process and what I was weaving began to take on deep symbology.”

“I hope that by sharing my art/weaving/way of processing that it may inspire others to explore tools...to help their own processing.”

Through weaving, Raven describes an embodied illustration of how **creative approaches can provide deep, meaningful and enlightening ways of processing and integration of suicide loss.**



Courtesy of renewedspirit.online

THEME 7

MAKING IT REAL: EMBEDDING LASTING CHANGE

One of the clearest threads running through this Fellowship was the need to move beyond gathering insights from people with Lived and Living Experience toward embedding those insights within lasting systems change.

Involvement and consultation alone are not sufficient. Impact occurs when Lived and Living experience of suicide shapes policy, governance, research, evaluation, and service design in sustained and visible ways.

Interviewees repeatedly emphasised that this level of change cannot be achieved through isolated activity or reliance on individual champions. Instead, embedding lived and living experience requires organisational readiness, shared responsibility, and alignment across teams, leadership, and governance structures.

Nichola Parry, Roses in the Ocean, explained: **“Embedding Lived and Living experience well requires the whole organisation to be prepared. It can’t just sit within one team.”**

Across the interviews, effective embedding of LLE was consistently linked to cultural change and coherent practice at every level of a system.

Where Lived and Living experience was embedded well, it influenced not only specific pieces of work, but also how decisions were made, how success was measured, and how accountability was held.

From consultation to systems change

In Australia, many services have moved from ad-hoc engagement toward system wide inclusion. This shift has changed both culture and practice.

Across the Australian services interviewed, many have moved from ad hoc engagement toward system-wide inclusion.

Safe Havens in New South Wales provide a clear example. Informed by lived and living experience, several services moved away from rigid risk assessment processes toward relational approaches grounded in trust and shared decision-making.

This demonstrates how embedding lived experience reshapes not only service design, but everyday interactions and organisational values.

StandBy Support After Suicide captures this approach through its guiding principle, “Nothing about us, without us.”^[37] This ensures that programs and policies are co-developed with people directly affected by suicide, so that insight is acted on rather than simply heard.

At a national level, Dr Lennart Reifels, Senior Research Fellow at The University of Melbourne, highlighted frameworks such as the Australian Government Suicide Prevention Planning Model and the ALIVE National Centre for Mental Health Research Translation. These initiatives partner with trusted lived experience organisations, including Roses in the Ocean, to embed ethical lived experience co-design within major national programs.

Dr Alan Woodward also emphasised that there is no single lived experience voice. Those bereaved by suicide, those who have attempted suicide, those who have supported others, and carers all bring distinct perspectives that must be represented in decision making spaces.

Together, these reflections show that authentic governance connects accountability, evaluation, and delivery. In these contexts, lived and living experience is not only consulted, but holds shared authority for outcomes.

Embedding through knowledge and research

Within academic and research settings, lived and living experience is increasingly becoming part of research design and implementation, rather than an afterthought.

Associate Professor Jacinta Hawgood, Griffith University, said:

“Lived and Living Experience is not a token in our work. It is part of our methodology. We are redesigning how research happens from the ground up; well essentially engaging in a way that allows Lived and Living Experience to take us (Academics) by the hand as experts on the journey”

Dr Lennart Reifels at The University of Melbourne, reinforced this approach:

“There’s strong merit in suicide prevention work that is co designed, not just consulted on, by people with lived experience.”

Professor Kairi Kõlves at Griffith University added:

“It’s about involving Lived and Living experience not just in research design but also in implementation, we need both.”

At the Black Dog Institute, Emma Elder described engaging large lived experience advisory groups from the outset of projects.

“We didn’t want tokenism. We wanted people who could challenge us and were supported to contribute meaningfully.”

Embedding LLE of suicide in research requires time, resources, and organisational commitment. Where it is done well, it produces evidence that is richer, safer, and more relevant. Griffith University’s AISRAP model^[38] demonstrates how partnership strengthens both ethical integrity and real-world impact in suicide prevention research.

From presence to shared authority

Embedding Lived and Living experience means moving from presence to power. It requires integration across governance, research, policy, and service delivery.

Evaluation should prioritise the experiences of those receiving support, and research is strongest when co designed and co led.

When lived experience moves from consultation to co ownership, systems begin to change at their core.

38 Griffith University, Australian Institute for Suicide Research and Prevention (AISRAP), 2023

39 Rothwell, S., Breaking Free from Stuck Points, 2023

EMBEDDING IN ACTION: What it Looks Like in Practice

These images are from the Roses in the Ocean Lived Experience of Suicide Summit 2025, where lived and living experience was embedded throughout the event, shaping conversations, design, and direction.

This was visible not only in formal sessions, but in the spaces created for connection, reflection, and peer support.

Contributors were involved in the design, delivery, and direction of conversations, rather than being included as standalone voices.

What stood out was a shift from contribution to influence, with lived and living experience informing how learning was shared, how discussions were facilitated, and how ideas were translated into action.

This reflects a wider pattern seen across the Fellowship. Embedding becomes visible when Lived and Living experience is integrated across structures, relationships, and decision making.



Community-led Safe Space model in practice



With fellow delegates at the Summit



Pre-summit workshop led by Bronwen Edwards, RIO CEO



With delegates Ken Bernard, Rayen Martinez and Stephen Rothwell

LIFELINE AUSTRALIA: EMBEDDING LIVED EXPERIENCE AT SCALE

LARGE SCALE SERVICES SHOW HOW LIVED EXPERIENCE CAN BE EMBEDDED WITHIN NATIONAL SYSTEMS

Lifeline Australia provides free, 24/7 crisis support through phone and digital services. It ensures that people do not face their toughest moments alone.

As a large organisation, Lifeline demonstrates how Lived and Living Experience can be embedded within structured systems to shape decision making and practice.

Dr Anna Brooks, Chief Research Officer, explained:

“We’ve shifted from just listening to actively involving people. Lived experience now shapes our national strategy, our data ethics protocols, and our funding submissions.”

This is supported through formal structures, including a Lived Experience Oversight Group that shapes project design and influences research and operational work.

Support is delivered at scale through trained staff and volunteers across both phone and digital services.

This model shows how Lived and Living Experience can be embedded at scale within a national system, shaping consistent, accessible crisis support over time, including visible support in public spaces.



Visible Lifeline crisis support information in public spaces, offering immediate access to help

KEN BARNARD – COMMUNITY ACTION AND SYSTEM INFLUENCE

Ken Barnard, a volunteer with lived experience of suicide bereavement, has translated his experience into sustained community and system-level action following the loss of his son.

At the time of this Fellowship, Ken was involved in a wide range of activities across his local area, from practical community support to strategic roles. His work included campaigning to improve local environments, such as organising clean-up efforts in social housing areas so that young people could play safely, as well as contributing to governance structures and national discussions on suicide prevention.

Ken's approach reflects a strong focus on the wider social determinants of wellbeing. **He recognises that people's experiences are shaped not only by individual circumstances, but by the environments they live in**, including housing, community safety, and access to support.

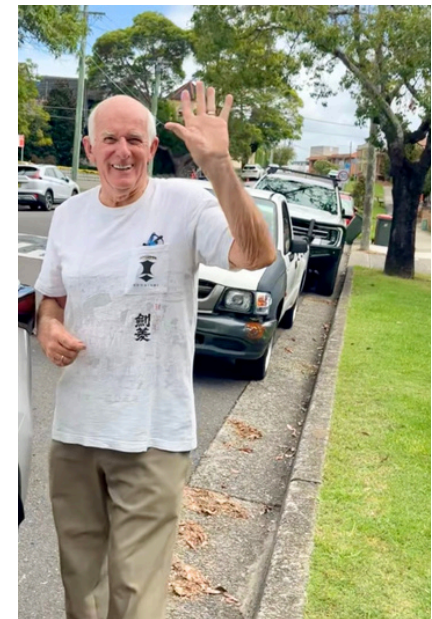
His work spans both practical and strategic action. This includes direct support, such as helping people move into and furnish homes, alongside influencing systems through roles on panels and committees, including involvement with Suicide Prevention Australia.

Ken's contribution challenges narrow understandings of Lived and Living Experience. It shows how this can inform leadership, advocacy and community change, not just personal sharing.

As Ken reflected:

“Everyone has got a story.”

His work shows how Lived and Living Experience, when supported and recognised, can extend beyond individual contribution and become **a sustained force for change within communities and systems.**



Voice of Lived Experience: Jimmy Morrison

Peer Work Leader, Former Soldier, System Disruptor
Medicare Mental Health Centre, Penrith

Jimmy Morrison's leadership brings Lived and Living Experience of military trauma and community work into practice.

At Penrith, people can choose to meet with a peer worker or a clinician. He describes the importance of creating real choice within services:

“We need to shift from providing crisis response to providing space for people’s experiences and how they want to be heard. Before we begin, I tell people I’m not a clinician. I’m a person with lived experience. If they’d prefer to speak to a clinician, they can, immediately.”

Jimmy challenges command and control cultures, including gendered norms within care systems:

“Men can’t cry. Women can’t get angry. We’re trying to undo that.”

Through reflective supervision and Discomfort Agreements, emotional expression is normalised within peer practice. He reflects on the lasting impact of meaningful connection:

“You can have five conversations that don’t affect you, and then one that stays with you for three days.”

He also highlights the ongoing stigma around emotional expression:

“Crying is still frowned upon. But why can’t we cry when we’re holding people’s pain?”

Jimmy describes peer work as cultural reclamation, reconnecting people to relationships, story, and collective healing:

“We’re returning to story, to relationships. It’s a form of decolonisation.”

PRINCIPLES FOR PRACTICE: GATHERING SUICIDE LIVED AND LIVING EXPERIENCE

These Principles translate the Fellowship's findings into practical guidance for organisations seeking to involve suicide Lived and Living Experience safely, ethically, and meaningfully.

1

Safety First

Safety must be designed into every stage of involvement, not added as an afterthought. This includes preparation, briefing, debriefing, follow-up, and access to appropriate support. Readiness is personal and can change over time. People must be able to pause, step back, or decline involvement without pressure or consequence. Cultural safety is central and will look different across communities and contexts.

2

Purpose and Transparency

Organisations must be transparent about why lived and living experience is being gathered, how it will be used, who it is for, and where influence sits. Only information that is genuinely needed should be requested. Consent should be treated as ongoing, not one-off, and revisited before reuse, publication, or dissemination. Closing feedback loops is essential so contributors can see what changed as a result of their involvement.

3

Respectful Language

Language shapes safety, understanding, and power. Organisations should use people's own words wherever possible, avoid labels and deficit framing, and take care not to medicalise grief or distress by default. Language choices in services, research, policy, and public communication should invite dignity, agency, and inclusion. Media and public outputs must follow safe-language principles and be reviewed with people who have Lived and Living experience.

4

Meaningful Involvement

Lived and living experience should be involved from the beginning, shaping questions, priorities, and decisions rather than responding to pre-set agendas. Organisations must be honest about the scope of influence and avoid overstating participation. Power sharing includes embedding lived experience within governance, leadership, recruitment, and decision-making, and partnering with trusted lived-experience organisations to support ethical engagement.

5

Sustainable Roles

Where suicide-specific peer roles exist, they should be clearly defined, properly supported, and recognised as skilled professional roles. Safe practice requires boundaries, reflective supervision, autonomy, and flexibility. People can contribute meaningfully while still living with the impacts of suicide experience when the right structures are in place. Organisations should support transitions into new roles without stigma and recognise that sustainability depends on care, not endurance.

6

Inclusion and Equity

Involvement must be accessible in practice, not just in principle. Barriers such as cost, travel, time, childcare, language, and technology should be actively addressed. Organisations should seek to include voices that are often missing and design with intersectionality in mind, recognising how race, culture, identity, age, disability, sexuality, gender, class, and geography shape experience. Creative, cultural, and non-verbal forms of expression should be recognised as valid ways of contributing.

7

Prepared Systems

Safe involvement depends on organisational capability as much as individual readiness. Staff, leaders, and professionals need preparation and training to work confidently and ethically with lived and living experience. This includes understanding roles, boundaries, emotional impact, and shared responsibility. Systems should adapt to real-world workforce conditions while maintaining care, safety, and integrity.

8

Reflection and Improvement

Lived and living experience should be integrated into research design, analysis, evaluation, and authorship, not added retrospectively. Services and initiatives should be evaluated from the perspective of those receiving support. Organisations must create feedback mechanisms, acknowledge and repair harm when it occurs, and use learning to strengthen future practice.

9

Policy and Infrastructure

For change to last, lived and living experience must be embedded within policy, commissioning, and national frameworks. Funding, contracts, and quality assurance processes should reflect good LLE practice. Formal partnerships with trusted lived-experience organisations help ensure ethical recruitment, involvement, support, and governance. Long-term investment in infrastructure is required to sustain suicide peer roles and lived and living experience leadership over time.

RECOMMENDATIONS

This Fellowship identifies a clear gap in the UK between national policy ambition and practical guidance for involving people with suicide Lived and Living Experience.

While national strategies emphasise the importance of Lived and Living Experience, there is currently no UK-wide operational framework to support consistent, safe, ethical, and meaningful practice across sectors.

Across UK interviews, people described being invited to share deeply personal experiences without adequate preparation, clarity, or follow-up. Organisations also reported uncertainty about how to involve people in ways that are safe, respectful, and effective. In contrast, examples from Australia demonstrate how structured frameworks can support safer, more purposeful, and more sustainable practice.

PRIMARY RECOMMENDATION

The development and implementation of a UK-wide National Framework and Practice Standard for Gathering and Involving Suicide Lived and Living Experience.

This framework should provide clear practice standards, practical guidance, structured training, and implementation tools to support consistent, safe, and ethical practice across sectors.

Development should be overseen through an independent, transparent partnership bringing together people with lived and living experience, practitioners, researchers, policy leaders, and sector organisations. This will ensure credibility, diversity of perspectives, and trust.

The framework should be open-access, co-produced from the outset, and designed for use across statutory, voluntary, academic, and community settings.

SUPPORTING RECOMMENDATIONS: Five priorities for national action

1 | National Framework and Tools

The framework should build on existing best practice, including lived-experience-led models, international guidance, and UK policy. It should include practical tools, templates, and examples to support real-world application across sectors.

2 | Embedding Co-Production and Power-Sharing

People with suicide Lived and Living Experience must be supported, prepared, and appropriately compensated, and involved at all levels of development, governance, and implementation. This includes roles in leadership, decision-making, and system design.

3 | Workforce and Organisational Readiness

A consistent national approach to training and workforce development is required to support safe and effective involvement. Organisations should be supported to assess and strengthen readiness, including culture, systems, policies, and workforce capability.

4 | Policy, Commissioning and Funding

The framework should be embedded within policy, commissioning, and quality assurance processes. Expectations should be clearly defined and reflected in funding criteria, service specifications, and evaluation.

Funding should support involvement, including preparation, facilitation, supervision, and follow-up.

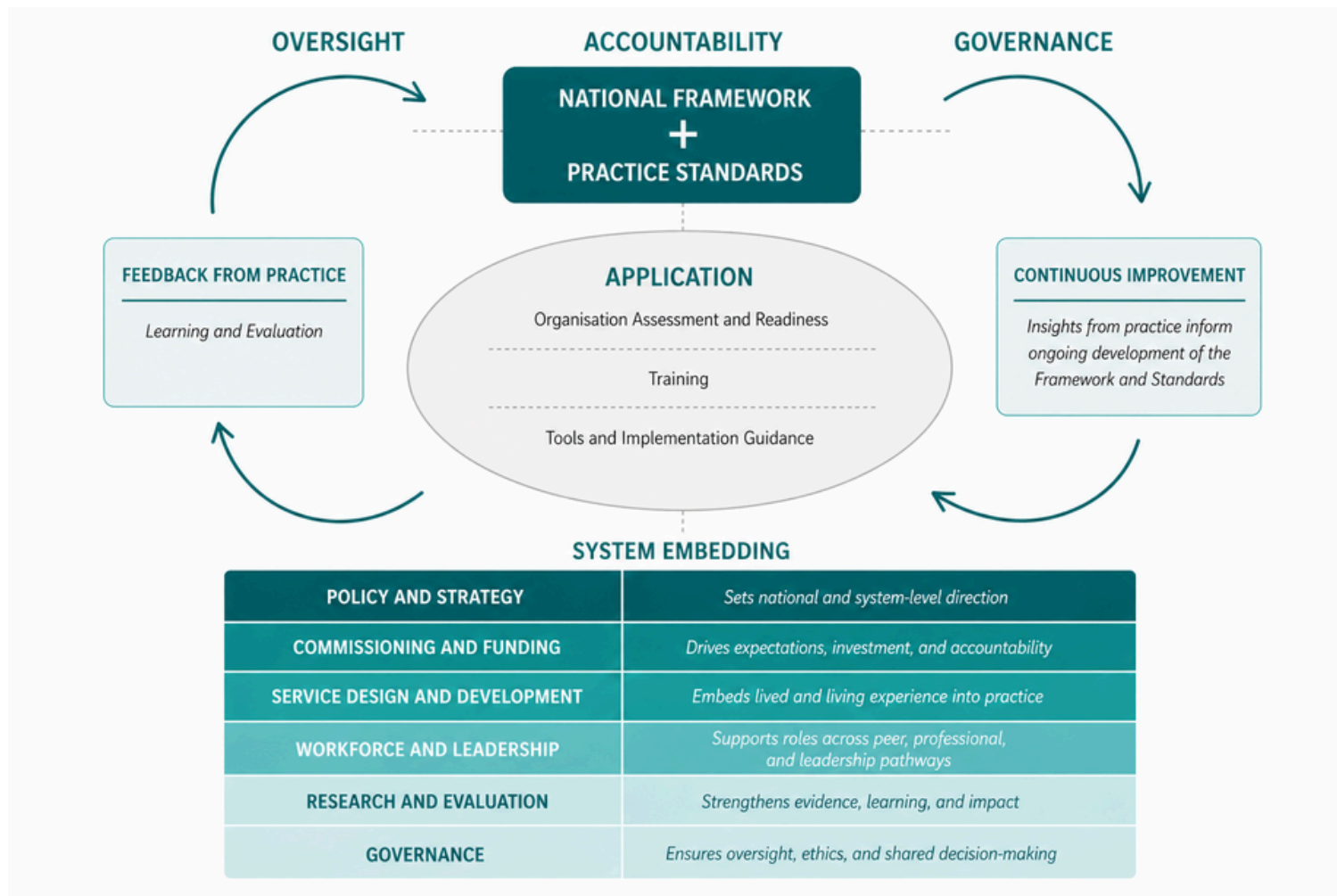
5 | Sustainability and Accountability

Long-term investment is needed to sustain suicide peer roles and lived and living experience leadership across sectors.

Clear accountability and oversight mechanisms should support consistent, safe, and high-quality implementation.

Embedding Good Practice for Gathering Lived and Living Experience

The diagram below shows how the recommendations connect as a coordinated system, supporting the development, implementation, and sustainability of safe and meaningful involvement.



NEXT STEPS

The next phase is to translate these findings into practical application through the development of a coordinated national approach.

Phase 1: Co-Design and Development

Establish an independent national partnership to co-produce the framework, bringing together people with lived and living experience alongside statutory, voluntary, academic, and community sectors. This phase should define governance, principles, standards, and practical tools, supported by independent oversight to ensure credibility, transparency, and trust.

Phase 2: Testing and Refinement

Pilot the framework across a range of settings and sectors to ensure it is practical and effective in real-world settings. This phase should include structured feedback, evaluation, and refinement to strengthen guidance and support consistent application.

Phase 3: Implementation and Scale

Embed the framework within policy, commissioning, workforce development, and organisational practice. This includes delivering training, developing supporting infrastructure, and enabling adoption across the UK to ensure long-term, sustainable impact. Ongoing oversight should support consistent implementation, monitor adherence to standards, and enable continuous learning and improvement across sectors.

Delivery will require coordinated leadership, cross-sector collaboration, and sustained investment. Without this focused development, the gap between policy ambition and practice is likely to remain.

ACKNOWLEDGEMENTS

I am deeply appreciative of everyone who took part in and supported this research both in the UK and Australia. This work is grounded in your voices. Without you, there would be no project. Your contributions honour your own experience and the people you love.

To everyone who has shared your lived and living experience in order to make a difference, your courage, honesty and willingness is what makes change possible.

I am grateful to the Churchill Fellowship for the opportunity and funding to undertake this research, and to other Churchill Fellows who supported my application, shared their experience, and offered their time and wisdom along the way.

Completing this report has not been straightforward. There were moments when the challenges felt heavy and the project close to stopping. Perseverance and a deep belief in why this work matters, has carried me through.

During this time, the support of my family and close friends meant everything. They celebrated with me when I received the news of the Fellowship and understood my need to make a difference; their continued belief in me has kept me going throughout this journey. I am grateful to you all.

Inviting me into your homes, sharing meals, walking with me along the beach, and offering me places to rest in unfamiliar places sustained me more than you may realise.

**By sharing what we've lived through,
we create something larger than ourselves,
a chance for others to find hope, safety and change.**

in memory of dad



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