GUIDELINES ON PATIENT AND FAMILY ENGAGEMENT IN CRITICAL CARE RESEARCH AND REGISTRIES

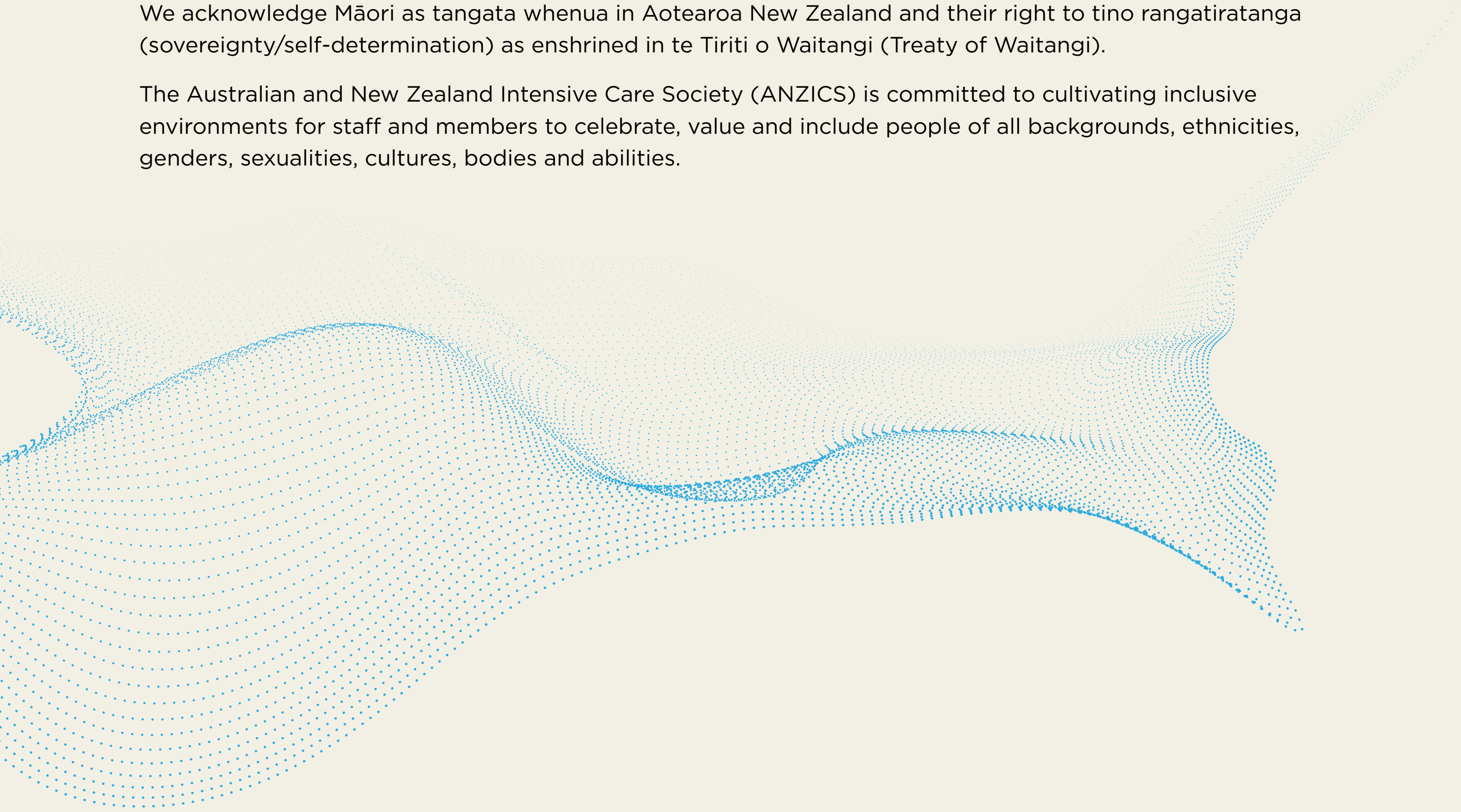
ANZICS

Acknowledgment of First Nations Peoples

We acknowledge Aboriginal and Torres Strait Islander peoples and communities as the Traditional Custodians of the land we work on and pay our respects to Elders past and present. We recognise that their sovereignty was never ceded.

We acknowledge Māori as tangata whenua in Aotearoa New Zealand and their right to tino rangatiratanga (sovereignty/self-determination) as enshrined in te Tiriti o Waitangi (Treaty of Waitangi).

The Australian and New Zealand Intensive Care Society (ANZICS) is committed to cultivating inclusive environments for staff and members to celebrate, value and include people of all backgrounds, ethnicities, genders, sexualities, cultures, bodies and abilities.



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Foreword

Written by Belinda MacLeod-Smith and Manoj Saxena

It is with great respect that I commend these guidelines to our community of clinicians, researchers and lived experience representatives. They mark a significant step in strengthening the voice of patients and families in critical care research across Australia and Aotearoa New Zealand.

At their heart, these guidelines affirm that engagement is not a token gesture but a structured, ethical, and enduring partnership. They call us to prepare carefully—by setting clear expectations, securing appropriate approvals, and ensuring patients and families are supported from the earliest stages of involvement. They are a reminder to recruit in ways that are respectful and transparent, to provide induction and training so that contributors feel confident in their role, and to acknowledge and resource their contributions through fair reimbursement and regular feedback.

The guidance also highlights what is essential for meaningful partnership: language that is clear and accessible, timelines that are realistic, and processes that safeguard privacy and psychological safety. Importantly, they point us toward equity—ensuring engagement with First Nations peoples, Māori, culturally and linguistically diverse communities, people with disability, bereaved families, and children and young people, each on their own terms and in culturally safe ways.

In this way, the guidelines echo the principles enshrined in the *Australian Charter of Healthcare Rights:* respect, partnership, information, and the right to be heard.[1] Just as patients and families are entitled to these rights in care, so too should they be upheld in the research that shapes future practice.

To all researchers, I extend this challenge: be as brave and vulnerable in your engagement as those who survive a critical care experience. We entrust you with our stories and our scars. Your task is to meet that courage with humility, curiosity, and commitment. If we do so together, research will not only generate knowledge—it will foster trust, equity, and healing.

Belinda MacLeod-Smith
ICU Family Member and Lived Experience Representative
Communication and Engagement Strategist, Safer Together Program, Safer Care Victoria

Research in critical care exists at the intersection of urgency, uncertainty and profound human experience. The patients we serve are often among the sickest in the health system, and their families are asked to navigate decisions in moments of deep vulnerability. For this reason, research in intensive care must not only be scientifically robust but ethically grounded, socially responsive and aligned with the needs and values of those most affected by critical illness.

The National Health and Medical Research Council (NHMRC) recognises that involving patients and communities across the research lifecycle strengthens the quality, relevance, and translation of health and medical research. According to the NHMRC's *Expectations and Value: Framework for Effective Consumer and Community Engagement in Research*,[2] engagement aims to:

- ensure research is responsive to community needs and values
- enhance the relevance, acceptability and impact of research
- promote fairness, equity, inclusion and diversity
- improve research quality, ethical rigour and accountability
- support meaningful partnerships and shared decision-making
- optimise translation into real-world benefit

In critical care, these objectives have unique resonance. Engaging survivors, family members and community representatives helps ensure that outcomes reflect what matters most—survival with good neurological function, physical recovery, psychological wellbeing, and family support. Partnerships with lived experience experts can strengthen research governance, refine consent processes for incapacitated patients, and build public trust in ethically complex trials. They also improve translation, ensuring that findings shape models of care that are acceptable, equitable and grounded in lived experience.

Lived experience expert engagement in clinical research is still a relatively new development internationally and within Australia and New Zealand. National and international frameworks supporting patient and family partnership in research have emerged only in the past 10–15 years,[3] with the first Australian policy statement released in 2016. It follows that current rates of lived experience expert engagement in critical care trials remain modest—reflecting the youth of this movement rather than a lack of commitment by researchers. Clinician-led trial networks such as the Australian and New Zealand Intensive Care Society Clinical Trials Group (ANZICS) Clinical Trials Group have long focused on patient-centred outcomes and ethical conduct, providing the scientific and organisational foundation upon which meaningful lived experience expert partnerships are now being built.

While engagement enriches research by bringing perspectives grounded in lived experience, the identification of research priorities and study questions must remain guided by clinical expertise and methodological feasibility. Skilled clinicians and investigators have a crucial role in recognising gaps in care, identifying questions that can be answered with scientific rigour, and ensuring that lived experience expert input is integrated meaningfully within these frameworks. In this way, lived experience complements professional expertise, strengthening both the ethical foundations and practical relevance of research.

These principles align directly with the NHMRC's current *Health Research Priorities 2024–2027*.[4] Engagement with Aboriginal and Torres Strait Islander peoples ensures that intensive care research is culturally safe and equitable. Collaborative approaches build resilience and trust in responding to emerging health threats and emergencies such as pandemics. Including the voices of survivors living with multiple long-term conditions ensures research addresses post-ICU recovery and quality of life. Finally, community perspectives on the development and use of artificial intelligence in health safeguard transparency and ethical integrity as digital tools become embedded in acute care.

Incorporating lived experience experts and communities as genuine partners across the research lifecycle—from concept development through dissemination—will strengthen the relevance, impact and accountability of critical care research in Australia and New Zealand. By embedding these partnerships within our scientific culture, we not only advance the rigour of our research but honour the trust of the patients, families and communities we serve.

Manoj Saxena
Chair, ANZICS Clinical Trials Group

Executive Summary

> **Relationships and time are the best foundation of great work.**
>
> Former ICU patient and lived experience representative

Introduction

There is growing impetus to partner with people with lived experience (PWLE; patients/lived experience experts and their families) in the design and delivery of health systems, services and research. The rationale for participation relates to voice, engagement, empowerment and advancement. The experience and wisdom of patients and caregivers —the end users of healthcare systems— can offer unique insights that may lead to improved health services and individual and family outcomes.[2] Research and quality assurance activities, such as clinical quality registries, are no exception. Evidence of patient and family engagement is increasingly required by funding bodies including the National Health and Medical Research Council (NHMRC)[2] and the Health Research Council of New Zealand,5 some academic journals,6 and healthcare policy and governance standards such as the National Safety and Quality Health Service Standards (Australian Commission on Safety and Quality in Health).[7,8]

Historically, patient and family engagement in research has been considered challenging in the intensive care unit (ICU) setting. In the ICU, the patient 'voice' is often absent, diminished or replaced because of acute serious illness, such that patients may be unable to advocate for themselves, and this is compounded by the highly technical environment. As patients recover from critical illness, patient and family engagement can restore that voice, helping rebuild autonomy and a sense of self-efficacy.[9,10] Improved survivorship after ICU admission has led toward a gradual shift to involve survivors and caregivers (including those who are bereaved) in critical care research, although the field is still evolving.[11-13]

In the Australian and New Zealand healthcare context, engaging with people with lived experience of a health condition (whether as a patient or family/whanau or carer) is often referred to as consumer and community involvement. To maintain consistency with the broader field, we use the term 'patient and family engagement' (PFE) in this publication. We also use Brown et al.'s (2015) inclusive definition of family as 'all the individuals whom the patient wants involved … regardless of whether they are related biologically, legally, or otherwise'.[14]

While PFE has many benefits to individuals and health systems, it is not without risk to patients, caregivers and organisations.[11-13] Researchers must consider resourcing, remuneration and diversity in lived experience expert representation, define the spectrum of engagement and the work required by lived experience experts, how to train lived experience experts, and issues of overburdening and sustainability. Without careful consideration of these factors, PWLE engagement can quickly become tokenistic and reduced to a check-box approach.

Objectives

The Australia and New Zealand Intensive Care Society (ANZICS) is working to consolidate binational efforts and establish a sustainable patient and family engagement infrastructure. This infrastructure will be used to support increased adoption of lived experience expert engagement into routine clinical quality registry work, critical care clinical trials and other research designs in Australia and New Zealand, via the ANZICS Clinical Trials Group (ANZICS CTG), as well as the work of the ANZICS Centre for Outcome and Resource Evaluation (ANZICS CORE). The objectives of these Guidelines are to support the critical care community to understand the current landscape of PWLE engagement in research, provide expert guidance and references to contemporary literature on this topic, and highlight practical resources to support engagement of patients and families in critical care research.

Methods, Key Findings and Recommendations

These Guidelines were developed and written in partnership between clinicians, researchers and people with lived and living experience of critical illness from across Australia and New Zealand. They were informed by a scoping review of the existing international adult and paediatric ICU literature and a comprehensive audit of ANZICS CTG and Paediatric Study Group-endorsed research over the past five years (described in Section 1).

The key recommendations and best practice points for patient and family engagement in critical care research and clinical quality registries appear in Sections 2–5 of the Guidelines and are also summarised in the table below for convenience.

2 Section 2: Practical Considerations When Building and Sustaining Effective Partnerships

Researcher preparation

Document the anticipated engagement plan over the life of the project. This should be malleable and discussed with the lived experience experts engaging with the project.

Check local state or area remuneration guidance for lived experience experts and seek funding permissions. A list of available remuneration guidelines appears in Appendix E.2.

Check if local institutional guidelines and resources are available to support engagement activities.

Identify training requirements for researchers and lived experience experts to support the engagement. Many organisations and health networks provide free online courses for both lived experience experts and researchers. Details of training resources are provided in Appendix E.2.

Learn, understand and engage with decolonising practices when engaging with Aboriginal, Torres Strait Islander and Māori lived experience experts and communities.

Identifying lived experience experts who may wish to participate in research engagement activities

Both direct and indirect approaches can be used to invite patients and families to participate in engagement activities.

Consider the setting for advertising—a waiting room or kitchen area may be less intrusive than advertising in a patient's room.

Provide clear information about the role and purpose of engagement but be open to change after early discussion with lived experience experts. Include information about the potential beneficial outcomes of engagement activities.

Invitations to engage should list the skills needed.

Provide a variety of contact methods for lived experience experts to communicate their interest. This can include email, phone number, link or QR code to an enquiry form.

Give lived experience experts ample time to consider their decision to engage and provide multiple opportunities for them to ask questions about the engagement role.

Prior guidance suggests that 3 months following hospital discharge is a suitable time to approach lived experience experts directly to invite their participation in engagement activities.

If making a direct approach to a lived experience expert, introduce yourself and your role first. Check it is a good time to discuss the partnership opportunity.

Practical considerations for sustaining the partnership

Induction. Discuss and agree how the participation will work, explore what the lived experience expert partners want to contribute, and share power in this process. Induction can be supported by the ANZICS People with Lived Experience Engagement Pack (Appendix E.1). This includes a welcome letter, position description, engagement contract, confidentiality agreement, remuneration agreement, log of hours, expense claim form, and expression of interest form.

Check in regularly (annually or biannually) with lived experience experts to see if they are still keen/able to partake in engagement activities. This may include bidirectional feedback between the researcher and lived experience expert about what is working well and what needs to be improved. Consider introducing a transition process for lived experience experts who wish to leave a project (e.g., facilitation of a ‘handover’ to an incoming lived experience expert). This may aid with any feelings of guilt or abandonment in needing to leave a project.

Use language that is easy to understand. Use lay language (avoid academic jargon and abbreviations) when holding discussions and meetings with lived experience experts so that everyone has an equal understanding. This helps to increase confidence, trust and respect between researchers and lived experience experts.

Be realistic about timelines and involvement. Set out a realistic timeline for tasks to be progressed. Communicate regularly via email/telephone between meetings.

Maintain privacy, confidentiality and psychological safety. Lived experience experts should be supported to feel safe to share their experiences and insights (especially as accounts of their experiences in the ICU may be traumatic). Lived experience experts should be given the choice of anonymity or confidentiality in disclosure of personal experiences and should maintain the confidentiality of other lived experience experts involved.

Have a plan for dealing with the distress that a lived experience expert might experience during or after engagement activities.

Reimburse lived experience experts for any out-of-pocket expenses related to engagement activities and remunerate them for their time. However, some lived experience experts may prefer not to be reimbursed and/or remunerated for altruistic reasons. These preferences should be discussed as part of the induction process to the project and revisited periodically. Seek local jurisdictional and organisational guidance on appropriate reimbursement and remuneration. Lived experience experts should be encouraged to seek independent advice about the implications of remuneration for tax or social security payments.

Across all stages of research, it is important to acknowledge the considerable, meaningful contribution of lived experience expert engagement by regularly reaching out to lived experience experts, preventing them being overburdened, and reassuring them that the researchers will support them as much as possible. Poor maintenance of this relationship may lead lived experience experts to see their involvement as tokenistic and transactional rather than meaningful, trusting and collaborative.

Follow legislative and policy guidance. When undertaking engagement work in Australia and Aotearoa New Zealand, be aware of the key national legislative and policy documents that underpin it.

3 Section 3: Guiding Principles for Patient and Family Engagement in Critical Care Research and Registries

Patient and family engagement in clinical research can occur across the research lifecycle: planning, design, conduct, interpretation and dissemination.

Research planning. Ideally, begin patient and family engagement in the planning phase. Strategies include co-design workshops or focus groups, gathering feedback from service user groups, or structured approaches to research prioritisation and question development, such as the James Lind alliance Priority Setting Partnership. Represent lived experience experts in funding applications to recognise their contribution and ensure their involvement is resourced.

Research design. Lived experience experts can co-design research questions, define eligibility criteria, select or develop patient-centred outcome measures, guide data collection methods to ensure acceptability and feasibility, co-design consent materials and processes and tailor recruitment strategies, and guide how results are communicated to participants.

Research conduct. Include lived experience experts on advisory panels, steering committees, study management teams and other governance groups. Work with lived experience experts to co-design improved participant retention initiatives and co-develop communications about study progress. Encourage PWLE-led substudies on aspects of the research and co-data collection.

Research interpretation. Lived experience experts can be engaged with data interpretation and analysis in many ways, depending on the research methodology. For qualitative approaches, lived experience experts can be involved in data interpretation at various levels, including consultation, development and/or application. When using quantitative methodology, involvement of PWLE in quantitative research may add critical context to numerical data, guide variable selection, and model building. Lived experience experts can ensure findings are meaningful and actionable for patients and communities and they can partner to explore unexpected or unusual findings.

Research dissemination. Lived experience experts can ensure that research outputs are communicated in ways that are meaningful and accessible to diverse audiences. Opportunities for PFE in dissemination include academic publications, conference presentations, lay summaries and infographics, community outreach, media engagement and advising on implementation tools. Lived experience experts can also be involved in research translation and advocacy for research results.

To ensure that clinical quality registries remain relevant, ethical and responsive to community needs, patient and family engagement should be embedded across key aspects of registry operations, including governance (inclusion of lived experience experts on advisory panels and governance structures), indicator selection, data interpretation, development and oversight of patient-reported outcome and experience measures and equity considerations (ensure representation of vulnerable and priority populations; respect Indigenous data sovereignty).

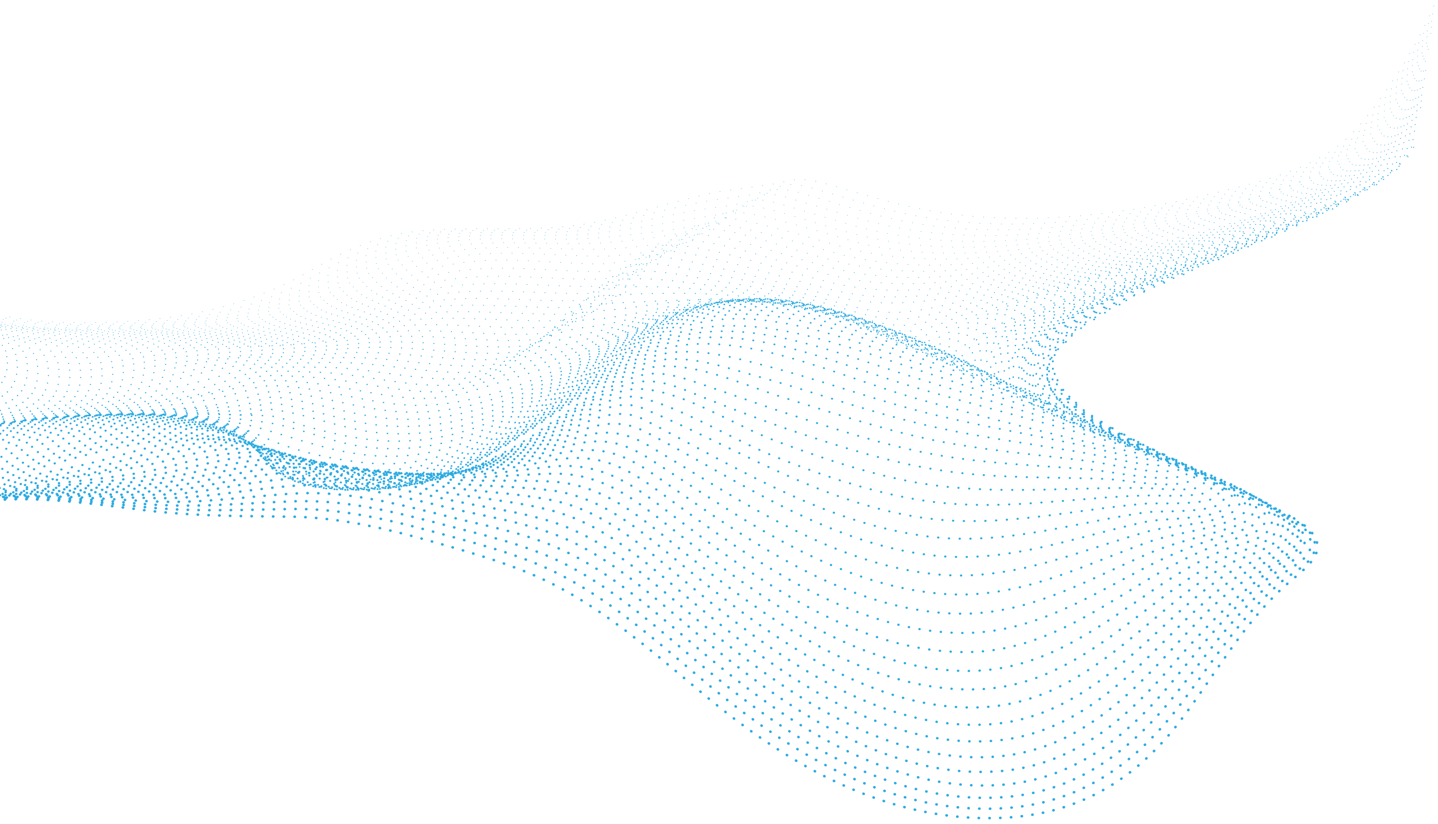
4 Section 4: Measuring the Impact of Patient and Family Engagement

In the initial stages, the team should meet to identify the impacts of engaging people with lived experience that are most important to the research and those involved.

Assess both positive and negative impacts of research engagement to avoid positive bias. A list of tools that can guide evaluation of impact when lived experience experts are engaged is available in Appendix C.

Researchers and PWLE can modify existing tools to ensure that they are assessing the most important impacts of their study.

Report involvement of PWLE comprehensively in all research outputs.



5 Section 5: Applying the Principles of Engagement in Partnership with Diverse Groups

Engaging with Aboriginal and Torres Strait Islander peoples: Effective communication and engagement is about ensuring Aboriginal and Torres Strait Islander peoples have control over research that affects them, shaping knowledge production in ways that support community wellbeing, cultural continuity, and self-determination.

Engaging with Māori: To engage meaningfully with Māori patients, whānau and communities, researchers must understand Māori perspectives of health and how colonisation has shaped and suppressed Māori hauora (health and wellbeing). Be guided by frameworks such as the Hui Process, the Meihana model and Te Wheke.

Other considerations when engaging with First Nations peoples: Recognise and respect First Nations people’s right to identify their own research priorities. Co-design research projects and methodologies with PWLE and communities. Ensure free, prior and informed consent by lived experience experts participating in research engagement activities. Provide adequate resourcing and support for leadership and participation. Be sensitive and respectful of the cultural load borne by First Nations people. Uphold principles of Indigenous and Māori data sovereignty and governance.

Strengthening research with other culturally and linguistically diverse communities requires defining the purpose of engagement clearly, identifying key communities and participants, considering the feasibility and timing of engagement, and mapping out the engagement continuum.

For gender-responsive research, acknowledge gender diversity, foster safe and inclusive spaces, enable meaningful participation, respect privacy and autonomy, embed gender considerations throughout, and respect pronouns.

When working with people with disabilities, enquire about what support is needed or how the engagement processes might need to be modified to enable participation. Set flexible meeting arrangements (consider timing and formats such as online/in-person, provide accessible facilities and transport, cater for support persons and animals).

When working with bereaved people, plan for how potential issues due to the grief experience might be resolved together. As relevant, use the hospital’s consumer liaison team, complaints management team, consumer engagement team, and psychology staff to support participation. Expect that some bereaved people will provide shorter-term commitment than others and consider planning a sensible and respectful strategy for maintaining support over time.

When engaging children and young people, use flexible participation methods, with convenient meeting times and locations. Clearly define roles and expectations. Provide information, discussions and activities appropriate to participants' age and development. Offer support and training from researchers and trusted adults. Ensure all participation is accessible, regardless of age, abilities, literacy or technology access. Include engaging activities that allow children and young people meaningful opportunities to share their views. Consider practical support for carers (e.g., waiting area, refreshments, internet access).

Researchers must uphold child protection requirements when engaging with children.

Impact and Conclusion

Advances in PFE in healthcare in the past decade have been substantial, particularly in research. Within the specialty of critical care, involvement of lived experience experts in research and clinical quality registries is expanding rapidly. However, critical care does not have the same extensive history and maturity of PFE practice and infrastructure as other disease-specific cohorts. Challenges in Australia and New Zealand may relate to the availability of lived experience experts, adequate resourcing to support their contributions, and the expertise and availability of researchers to support engagement. ANZICS, the leading professional society for critical care in Australia and New Zealand, recognises this gap in health policy and research practice, which these Guidelines aim to close. The Guidelines are not proscriptive and do not mandate any specific level of engagement for any type of research project or clinical quality registry. Rather, the Guidelines are a valuable resource to be integrated with local recommendations. The Guidelines aid the community to understand the current landscape of lived experience expert engagement, provide expert guidance, refer to the most up-to-date literature on this topic, and highlight practical resources to support greater engagement of patients and families in critical care research and registries.

Patient and family engagement in clinical research can occur across the research lifecycle: planning, design, conduct, interpretation and dissemination.

Plan

Consider who, when, how, and for how long you will involve PWLE

Consider how you will resource and support their engagement

Include PWLE in research prioritisation and planning

Design

PWLE can co-design research questions, select patient-centred outcome measures, and guide consent and recruitment strategies

Consider how you might engage PWLE in grant funding applications

Conduct

Include PWLE on study management committees

Work with PWLE to co-design retention and communication strategies

Consider substudies led by PWLE

Interpret

Consider how PWLE co-investigators might contribute to data analysis and interpretation (both qualitative and quantitative data)

Disseminate

Consider whether PWLE co-investigators can present/ attend scientific meetings and include them as co-authors

Co-design lay summaries, media statements and implementation tools with PWLE

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All lived experience experts contributed to the design of the guidelines and review of the final guidelines. Lived experience experts **Dale Trevor, John Asgari** and **Kein Gan** reviewed the final draft of the guidelines. Other lived experience experts worked alongside the section chairs and other members to develop ideas, and assist with writing and review, described in the following section.

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Role of the Funder

The ANZICS Board provided a review of the final guidelines and endorsement.

Conception and Design

Kimberley Haines and **Yasmine Ali Abdelhamid, Ann-Marie Baker, Dale Trevor, Aisha Khan**, the section chairs and section members were responsible for the Guidelines' conception and all aspects of their design. All authors drafted and revised the guidelines to maximise the quality of its intellectual content.

SECTION

1

Background to Patient and Family Engagement in Critical Care Research

> **I have welcomed the opportunity to use my own experience in ICU to give back to the medical researchers who are improving and saving the lives of those who are critically ill.**
>
> Former ICU patient and lived experience representative

1.1 What is Patient and Family Engagement?

Patient and family engagement (PFE) is grounded in the concept of patient-centred care, in which patients and families move from the passive role of care recipient to active involvement in their care as shared decision-makers.[14] This departure from paternalistic clinical care has recently been mirrored in a shift away from paternalistic research: patients are now participants and partners in research (as members of research teams) and may no longer be viewed as 'subjects' of research.[15-18]

However, although the patient-centered and family-centred care movement in medicine has advanced overall, critical care medicine faces challenges.[11] These include the acute nature of critical illness, which can prevent and/or complicate patients and their families participating in care, coupled with the critical care environment, where emotional stakes are high, time is short, and surrogates play a key role.[19] The same factors have hindered the engagement of patients and family in critical care research, meaning it has been uncommon until recent years.

Patient and family engagement has been defined as 'an active partnership between health professionals and patients and families working at every level of the healthcare system to improve health and the quality, safety, and delivery of healthcare'.[14] This definition encapsulates five core concepts of PFE: Collaboration, Respect and Dignity, Activation and Participation, Information Sharing, and Decision-Making.[14] In addition, the Australian Commission on Safety and Quality in Health Care's (ACSQHC) Partnering with Consumers Standard states that 'Leaders of a health service organisation develop, implement, and maintain systems to partner with consumers. The partnership relates to the planning, design, delivery, measurement and evaluation of care. The workforce uses systems to partner with consumers'.[7]

Power sharing is at the core of patient and family engagement, and needs conscious attention throughout the partnering process, supported by guiding documents. Within critical care, a continuum of partnership begins at a basic level and progresses toward a more advanced partnership in which power is shared, as follows:

1. **Transactional** – based on 'giving back', with one-way communication and occasional interaction, in which patients and families have a relatively passive role
2. **Transitional** – two-way communication, consultation, and repeated collaboration, in which patients and families are more active in the dialogue although remain largely in a recipient role
3. **Transformational** – joint learning and sense-making based on authentic dialogue with frequent interaction, in which decision-making is shared and patients and families hold equal power with health professionals[11]

The Transformational level incorporates participatory research methods such as co-design and co-production in which power is shared equally. Co-design and co-production involve lived experience experts as partners in the planning and design, conduct and dissemination of the research, and there are usually equal numbers of health professionals and lived experience expert researchers in the team.

This critical care partnership continuum aligns with the International Association for Public Participation (IAP2) Spectrum, used commonly used in Western healthcare and applicable to critical care, consisting of Inform, Consult, Involve, Collaborate and Empower (Figure 1).[20] In the IAP2 spectrum, power to decide how and when to use the information provided by people with lived experience (PWLE) rests initially with the 'professional' researchers, and only at the final stage is there a genuine shift in power.

Figure 1. The International Association for Public Participation Spectrum

Increasing impact on the decision

	Inform	**Consult**	**Involve**	**Collaborate**	**Empower**
Public Participation Goal	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
Promise to the Public	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

1.2 Nomenclature

In the Australian and New Zealand healthcare context, engaging with people with lived experience of a health condition (whether as a patient or family or carer) is often referred to as consumer and community involvement. To maintain consistency with the broader field, we use the term ‘patient and family engagement’ (PFE) for this publication. However, when working with PWLE, consideration should be given to the language used, because not everyone will identify with the terms ‘consumer’ or ‘patient’ or ‘survivor’ or ‘lived experience expert’, and best practice is to check this at initial engagement meetings. We also adopted Brown et al.’s (2015) inclusive definition of family as including ‘all the individuals whom the patient wants involved … regardless of whether they are related biologically, legally, or otherwise’.[14]

1.3 The Importance of Lived Experience and the Different Meanings of Health

Patients and families provide subjective insights into critical care research, systems, clinical care, and environments. These insights cannot be gained without lived experience of those processes. PWLE can tell you how an event or process feels, their sensory perceptions, the parts that made them feel safe, and the factors that helped them to trust and understand the research in which they participated. Much of this cannot be observed or measured externally. Without mechanisms to collect this information and embed it within research practices, we may unknowingly and unnecessarily increase patients’ and families’ distress and trauma. We might also miss the opportunity to foster a therapeutic environment and ensure patient and family needs are met. Furthermore, PWLE may have their own research priorities, grounded in lived experience. Further, PWLE can provide insights beyond their experiences of receiving care; for example, they may contribute their professional and social perspectives. Meaningful engagement aspires to maximise the benefit of research to patients and families.

For First Peoples of Australia (Aboriginal and Torres Strait Islanders) the effective delivery of health care demands that dispossession, colonisation, racism, assimilation and denial of citizenship are considered.[21] Health has a diverse set of meanings for different people. For instance, in Australia, 'to be healthy' means more than the 'absence of diseases' for First Peoples. Rather, it means their 'healthy connection to themselves as family and Country with its spiritual aspects' remaining strong.[22] A 'whole of life' approach includes understanding the impact of 'self-determination, land and sea rights and influence and control over the policies that control [First Peoples’] destiny in Australia'.[23] For Māori, hauora is a holistic concept that involves the interconnectedness of physical, mental/emotional, spiritual and social domains of wellbeing.[24] Furthermore, Māori healing philosophies emphasise the importance of a connection to te taha wairua (spiritual domains) and the whenua (land) through whakapapa (ancestral connections).[25,26] Researchers wanting to engage meaningfully with Māori must think deeply about their own perceptions of health and wellbeing and seek to eliminate any biases that may intentionally/unintentionally undermine Māori healing philosophies. Health professionals and organisations striving to implement PFE face the challenges of competing world views and unidentified/unconscious positions of power.

1.4 What is the Current State of Patient and Family Engagement in Critical Care Trials Conducted in Australia and New Zealand?

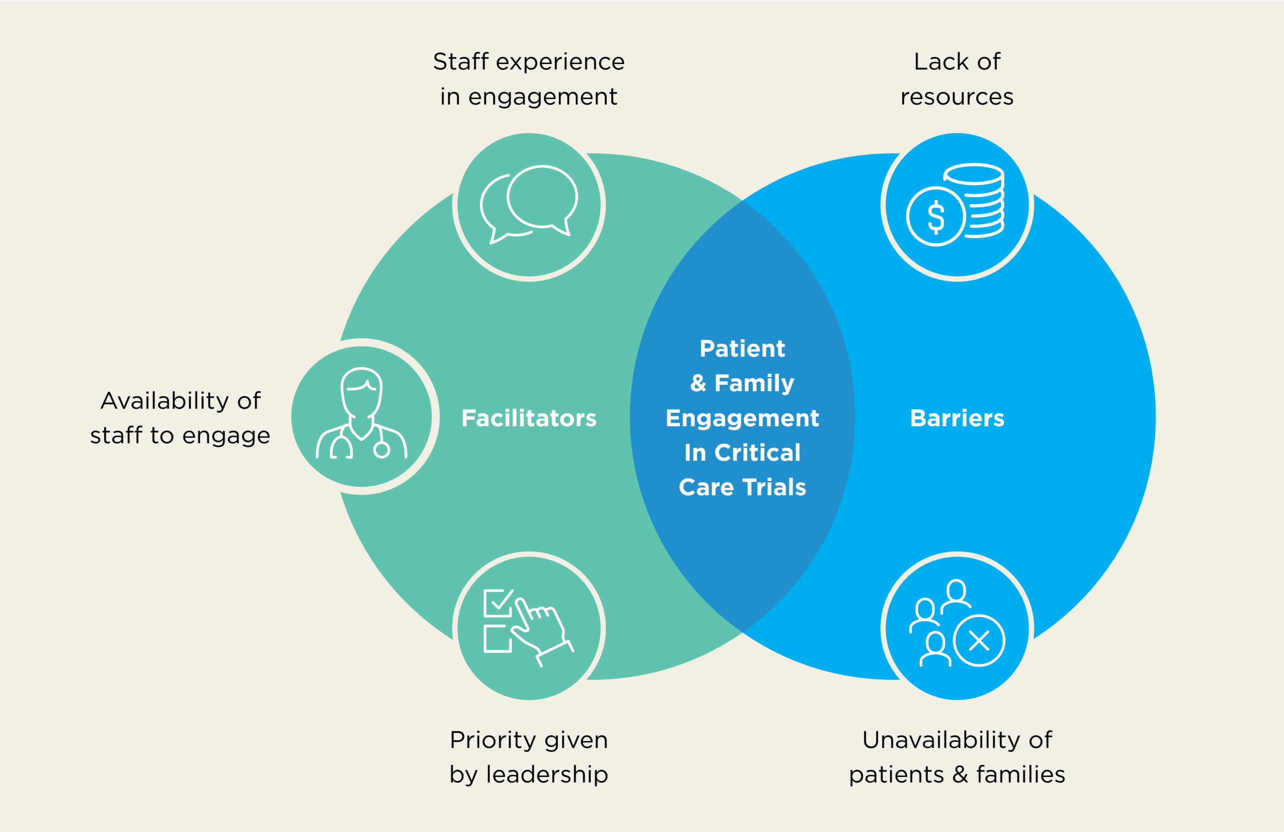
Adult critical care

In 2024, members of the ANZICS Clinical Trials Group (ANZICS CTG) Committee undertook a study of the extent of PFE in adult critical care research endorsed by the ANZICS CTG over the past 5 years.3 This study involved a two-stage process:

- a retrospective independent appraisal of PFE in study protocols, progress reports, and manuscripts
- a prospective self-reported survey of principal investigators and project managers to understand priority of engagement, types of activities, barriers and facilitators

Engagement was assessed using a modified version of an existing tool developed by the Canadian Critical Care Trials Group Patient and Family Partnership Committee, as well as the Guidance for Reporting Involvement of Patients and Public 2 (GRIPP2) tool.[27] In the 35 included studies, low rates of PFE in clinical trial protocols (8/35, 23%) and final manuscripts (0/10, 0%) were identified via independent appraisal, and there was a higher self-reported rate of engagement activities among ANZICS CTG-endorsed studies. The most common facilitator of engagement reported in the survey was staff engagement experience (12/28, 43%); lack of resources (12/28, 43%) was identified as a key barrier. Other facilitators and barriers are shown in Figure 2. This study highlighted the importance of adequate resourcing for engagement activities, including experienced personnel and funding.

Figure 2. Summary of facilitators and barriers to patient and family engagement in ANZICS-CTG endorsed trials



Adapted from Evertsz et al. (2025)[3]

Paediatric critical care

In 2024, the ANZICS Paediatric Study Group conducted a mixed-methods environmental scan of the current state of PFE in Australian and New Zealand (ANZ) paediatric intensive care (PIC) research, as outlined in the published protocol.[28] The aim was to identify barriers and facilitators and map trends in PFE in research to inform future strategies in the pursuit of more patient- and family-centred PIC research. The study was conducted in two phases:

- **Phase 1:** scoping review including published, unpublished and ongoing PIC research conducted from 2016 onwards
- **Phase 2:** semi-structured interviews with research teams and PWLE to gather insights about their experiences of PFE in PIC research, using content analysis to identify key categories

In Phase 1, 120 reports of ANZ-led PIC research from 2016 onwards were identified. Of these, 16 described engagement of patients and families as research partners (7 published articles and 9 unpublished studies). In Phase 2, 19 researchers (clinicians and academics) and 11 PWLE who had been involved in ANZ PIC research were interviewed. Four content categories emerged: trying to do the right thing, appreciating individual differences, being part of a team, and potential for harm.

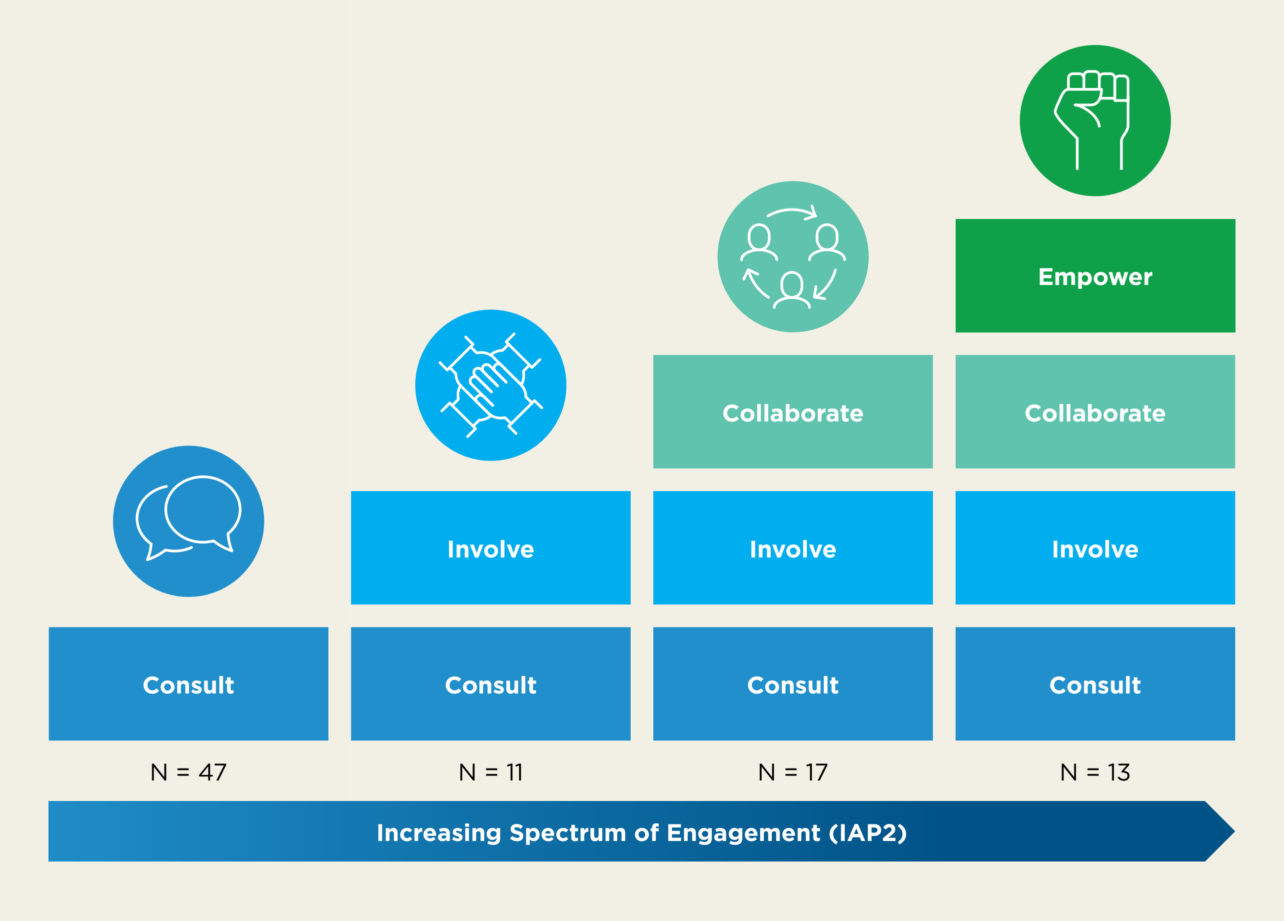
This study provided the first insights into patient and family engagement in PIC research within Australia and New Zealand. While clinician researchers continue to adopt and refine lived experience expert engagement practices, there is still a large gap between what is expected and what is occurring within the ANZ PIC research landscape. Further research and involvement of patients and families is needed to tailor guidance specifically to the PIC context.

What is the current state of the field globally?

To inform the background for these ANZICS Guidelines, a scoping review of the literature was undertaken in 2025.[29] The aim of the scoping review was to describe PFE in critical care research globally; including where it occurred in the research life cycle (identification and prioritisation of research, conduct and analysis of research, dissemination, and/or implementation), and any subsequent impact of PFE. Adult and paediatric critical care studies that reported PFE consistent with any level of the IAP2 Spectrum (Inform, Consult, Involve, Collaborate, Empower; see Figure 1) were included. Studies were excluded if they described engagement only at the first level of the IAP2 tool (Inform). OVID Medline, OVID Embase, PubMed, CINAHL and Web of Science were searched for studies published between 2016 and 2025; two reviewers screened all results and extracted data.

Of 4741 titles and abstracts screened, 47 studies met inclusion criteria. All 47 studies engaged patients and families at the Consult level on the IAP2 tool; only 13 (28%) of studies included PFE at all levels (Figure 3).[29] Three studies engaged patients and families at Consult and Collaborate levels, but omitted the previous levels. Demographic details of lived experience expert representatives were rarely reported. Patients and families were most frequently engaged in the development of surveys, interventions and study protocols (n=19, 40%). Engagement occurred mostly in the initial stages of research identification, prioritisation and design (n=47, 100%), with only 10 studies (21%) engaging patients and families at all stages of the research lifecycle.

Figure 3. Level of PFE across the IAP2 Spectrum in the scoping review of 47 global critical care studies



Emery et al, authors' own work

The scoping review found that few critical care studies globally had involved extensive, multi-level forms of engagement. There was minimal reporting on the impact of engagement activities on the research. Studies with higher levels of engagement, as defined by the IAP2, included more extensive PFE across the research lifecycle and were more likely to report its impacts on the research. The key resulting recommendations were that future studies should enhance the quality of reporting of engagement activities by including demographic details of patients and families and by clearly reporting methods and impacts of PFE using existing tools such as the IAP2 and GRIPP2.[29]

SECTION

2

Practical Considerations When Building and Sustaining Partnerships

> **I have been on a large [research] project that is well underway. I felt I didn't understand what was going on. The main research assistant who was running the project had to leave and a special person who had a background in consumer engagement took over the management of the project … this new worker was so enthusiastic to help me to work through things I am sure would not have happened otherwise. It is like I have walked out of a dark cave onto a sunny beach.**
>
> Former ICU patient and lived experience representative

Effective partnerships with lived experience experts rely on relationships that must be established, built and maintained in distinct phases, requiring consistent attention, flexibility and feedback. All phases should be supported and guided by governance structures.

2.1 Preparing for Engagement Activities

Researcher preparation

The researcher should begin by considering the purpose, scope and duration of the PFE required, and discuss these considerations with the lived experience experts being invited onto the project as partners. Define the scope of the project and the expectations regarding decision-making power at the outset, as well as avenues for feedback and accountability. Outline reimbursement expectations and time commitments at the beginning of the relationship and process of engagement. These early stages of preparation build the foundations for effective and ethical lived experience expert partnership in research. Lived experience experts have the right to understand what is involved, including potential benefits and risks.

Basic training in PFE is highly recommended for researchers and project managers (even if they are experienced clinicians or researchers). The Research Education and Training Program (RETProgram), an initiative of the Western Australian Health Translation Network, offers a free and brief introductory course called Consumer and Community Involvement in Health Research (see Appendix A.1). This training is relevant for patients, families and clinicians/researchers. Many of the organisations listed in Appendix A.1 also provide free online training options for both lived experience experts and researchers.

Decolonising work for researchers prior to engagement and ethical conduct

Research has historically been something that is ‘done on’ Aboriginal and Torres Strait Islander peoples and Māori without engagement, consent or benefits from participation.[30] Engagement with Aboriginal and Torres Strait Islander and Māori lived experience experts is essential to ensure that research is a constructive, mutually beneficial exercise. Researchers should learn about decolonising practices and engage with them within their work and wider lives, and follow ethical guidelines when engaging.

Key resources that can guide this journey include:

- *Decolonising Methodologies* by Linda Tuhiwai Smith.[30] This book is central to understanding Indigenous ways of knowing, being, and doing
- The CONSIDER statement by Tania Huia.[31] This provides a framework for the ethical reporting of data that involves Indigenous communities
- *A Māori perspective of health* by Sir Mason Durie.[24] This was the first paper to discuss what became known as Te Whare Tapa Whā. It also illustrates the lengthy journey towards health equity
- *Achieving health equity in Aotearoa: strengthening responsiveness to Māori in health research*, a research paper by Papaarangi Reid, Sarah-Jane Paine, Elana Curtis, Rhys Jones, Anneka Anderson, Esther Willing and Matire Harwood.[32] This explores how health researchers can be responsive to Te Tiriti o Waitangi when engaging in health research in Aotearoa New Zealand
- NHMRC *Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: Guidelines for researchers and stakeholders*[33]
- NHMRC *Keeping Research on Track II*[34]
- *Ethics in Aboriginal and Torres Strait Islander health research: Discussion paper.*[35] This discussion paper was commissioned by the Lowitja Institute and recommends ways funding bodies, government, research institutions, journals and individuals can uphold Aboriginal and Torres Strait Islander rights to safe and ethical research practice
- NHMRC *Statement on consumer and community involvement in health and medical research*[18]
- Australian Institute of Aboriginal and Torres Strait Islander Studies *Code of Ethics for Aboriginal and Torres Strait Islander Research*[36]

Identifying people with lived experience who may wish to participate in research engagement activities

There are different ways in which initial contact between researchers and lived experience experts can occur and lived experience experts are alerted to opportunities to participate in research engagement activities. Direct and indirect approaches are possible; both require clear communication about what is involved, the role of the lived experience expert, and remuneration.

Direct approach. This approach may involve an initial conversation with or written approach to a lived experience expert. Often these relationships form and evolve organically. Consideration should be given to the location and timing of approaches to lived experience experts. Previous guidance suggests that the optimal time to approach lived experience experts directly for engagement activities is 3 months after hospital discharge, although lived experience experts can indicate whether the timing is right for them to engage.[11]

Indirect approach. This approach involves advertising the opportunity for partnership via indirect avenues, such as flyers/posters/leaflets within hospitals in general areas such as ICU waiting rooms, and advertising via newsletters through charity and network groups and social media. Patients and families still in the ICU may prefer an indirect approach. The lived experience expert is empowered to make initial contact to learn more or officially commence the partnership. An indirect approach gives lived experience experts the time and opportunity to contemplate their involvement, with less pressure to engage in the partnership.

When thinking about how to identify people, remember to think broadly; for example, patients and families with experience of heart disease may also have experience of critical illness and may be linked to a critical care lived experience expert group. Consider support groups operating through social media, or seek out lived experience experts via advocacy and representative groups, or existing lived experience expert networks developed via research collaborations. This can help to identify individuals who are able to contribute to research based on their lived experience expertise and not just their experiences as recipients of care. PWLE often have broad connections that enable 'snowballing' – they can link you with others who might be interested in engaging. Appendix A lists some current lived experience expert groups and organisations.

Preparing and supporting lived experience experts

Planning for involvement is essential to ensure smooth orientation and lay the foundation for meaningful and successful lived experience expert engagement. Ask lived experience experts what they want to get out of the engagement and what/how they would like to contribute. Work as a team (professional and lived experience expert researchers) to achieve this. All engagement arrangements should be documented in an agreement that all parties understand and approve. The agreement should remain flexible, because lived experience experts' preferences for involvement may change throughout the research project. An example of such an agreement appears in Appendix E.1 in the ANZICS People with Lived Experience Engagement Pack.

If lived experience experts are part of the research team from the outset, then research ethics and governance approvals to engage with them should not be required. Usually, such approvals are only required if there is an intention to collect data from lived experience experts as research participants (e.g., in evaluation of the patient engagement approach).

Supporting lived experience experts means providing the right training and checking in regularly on what they might need to help them contribute effectively and to build their capacity to participate. It is important to discuss training needs with each lived experience expert. Training needs may vary depending on the nature and level of involvement.

Preparing lived experience experts to feel informed and confident to participate may require additional preparatory meetings with the lived experience experts before introducing them to the larger project team meetings. Such meetings enable lived experience experts and the project leads to get to know each other, form relationships, ask/answer questions, and for the researchers to explain the project, outline roles and expectations, and provide any pre-reading or background information. This allows both parties to tailor communication and engagement in the partnership. Before meeting with the larger project team, share plain-language meeting agendas with the lived experience experts, and check if they have questions. Similarly, interact with other project team members to see if they have preferences for how to engage and work with the lived experience experts.

If you have experienced lived experience experts in your group, you may consider setting up a mentoring arrangement in which one or more provides support and guidance to a new lived experience expert to help build capacity.

Lived experience experts' ability to remain involved can vary over time. Create clear pathways for continuing or stopping engagement, and review the process regularly.

Best Practice Points

Document the anticipated engagement plan over the life of the project. This should be flexible and agreed with the lived experience experts engaging with the project.

Check local state or area remuneration guidance for lived experience experts and seek funding permissions. A list of available remuneration guidelines appears in Appendix E.2.

Check if local institutional guidelines and resources are available to support engagement activities.

Identify training requirements for researchers and lived experience experts to support the engagement. Many organisations and health networks provide free online courses for both lived experience experts and researchers. The details of training resources are provided in Appendix E.2.

Researchers should learn about and apply decolonising practices within their work and wider lives when engaging with Aboriginal, Torres Strait Islander and Māori lived experience experts and communities.

Both direct and indirect approaches can be used to invite patients and families to participate in engagement activities.

Consider the setting for advertising—a waiting room or kitchen area may be less intrusive than advertising in a patient's room.

Provide clear information about the role and purpose of engagement, but be open to change after early discussion with lived experience experts. Include information about the potential beneficial outcomes of engagement activities.

Invitations to engage should list the skills needed.

Provide a variety of contact methods for lived experience experts to communicate their interest. This can include email, phone number, link or QR code to an enquiry form.

Give lived experience experts ample time to consider their decision to engage and provide multiple opportunities for them to ask questions about the engagement role.

Prior guidance suggests 3 months after hospital discharge is a suitable time to approach lived experience experts directly to invite their participation in engagement activities.

If making a direct approach to a lived experience expert, introduce yourself and your role first. Check it is a good time to discuss the partnership opportunity.

2.2 Additional Considerations for Building and Sustaining Relationships

Practical steps for nurturing ongoing connections

Patient and family engagement is not merely about working with PWLE in the short term—it is about fostering and building long-term, meaningful relationship over time by maintaining consistent communication between researchers, lived experience experts and family members.

Think about 'who' it is you want to engage with (patients, families) and whether any specific experience of critical illness is needed for your project (e.g., admission diagnosis or other characteristics). Remember to consider the elements of diversity (e.g. age, sexual orientation, ethnicity, race, gender, physical abilities/qualities), and how these identities intersect. People who have the time to contribute to PWLE groups are most likely to be older, retired or financially stable adults. If you want to engage with people from a diverse range of age groups or socioeconomic backgrounds, strategies such as flexible meeting times to accommodate work schedules will be required.

The number of PWLE that should be engaged will depend on the purpose and the scope of the project. Groups larger than 10 people can be difficult to manage. However, engagement with a sole lived experience expert may be insufficient unless they are very experienced, due to the potential for a power imbalance.

Where possible, consider engaging PWLE with a variety of levels of experience. As an example, a new and inexperienced lived experience expert may benefit from pairing them with a more experienced individual who can provide support and share knowledge about the role and expectations.

Once initial connections and relationships are developed, researchers should develop and implement strategies to nurture them. They might include:

- identifying a key contact person for the lived experience experts
- responding to contact from lived experience experts promptly, or letting them know you will reply when you can
- a newsletter or other means of providing research updates
- scheduled periodic meetings to provide information, even if brief and informal. Such contact helps lived experience experts stay connected to or withdraw from the project (if desired)
- meeting for refreshments in a mutually convenient location
- annual provision of certificates of appreciation for lived experience experts' contributions

Resourcing and sustainability

Working with lived experience experts requires adequate resources and a plan for sustainability. A single researcher or project manager could coordinate working with 1–2 lived experience experts, keeping in mind the principles outlined above. A lived experience expert group of more than 3 people will require more maintenance and resources, as outlined below.

- A central contact person is critical to foster relationships and ensure long-term engagement.
- Where possible, lived experience experts' expenses (parking, taxis) should be reimbursed.
- Remuneration or payment for time (in the form of money or a voucher/gift card) should be offered if possible. Remuneration guidelines vary by organisation and state (see Appendix E.2). Lived experience experts should be advised to seek independent advice about the implications of remuneration for tax or social security payments. Some lived experience experts will decline payment or gift vouchers, but they should be offered nonetheless. Some lived experience experts may prefer a donation to be made to a charity of their choice.
- If no remuneration is available, clarify this at the outset of the engagement process. This will influence the amount of engagement; for example, you cannot expect a lived experience expert to lead an intensive engagement process without remuneration, but commenting on research documents would be appropriate.

- Consider other ways in which lived experience experts could be recognised, beyond remuneration. Non-financial recognition includes co-authorship on publications, chief investigator listings on collaborative grant applications, and invitations to speak at scientific meetings. It is good practice to develop a policy about the non-financial aspects of recognition and reach an agreement with lived experience experts upfront.
- Some organisations require a declaration of conflicts of interest, and this is a valuable form of transparency. Examples of conflicts of interest include a lived experience expert having a financial stake in a company that is competing for a contract with the health organisation, or a lived experience expert who is also a healthcare provider being asked to provide a perspective on a service that intersects with their professional role.
- Prior to commencing engagement, consider:
  - the lived experience expert's level of participation in engagement activities
  - acknowledging that the lived experience expert's involvement can be ended at any time
  - provision of an honorarium (i.e., payment) as a gesture of the organisation's appreciation for participation
  - declaring that the lived experience expert does not hold an adjunct appointment with the organisation (if the organisation is a university)
  - declaring that the lived experience expert does not require an Australian Business Number (ABN) because they are not carrying on an enterprise in Australia related to this research (although they may require an ABN to invoice for their work)
  - the level of confidentiality required from the lived experience expert.

Consider the resources required to undertake the engagement activities and budget accordingly. An inadequate budget signals low commitment to the process of patient and family engagement. Items to consider in budgeting include:

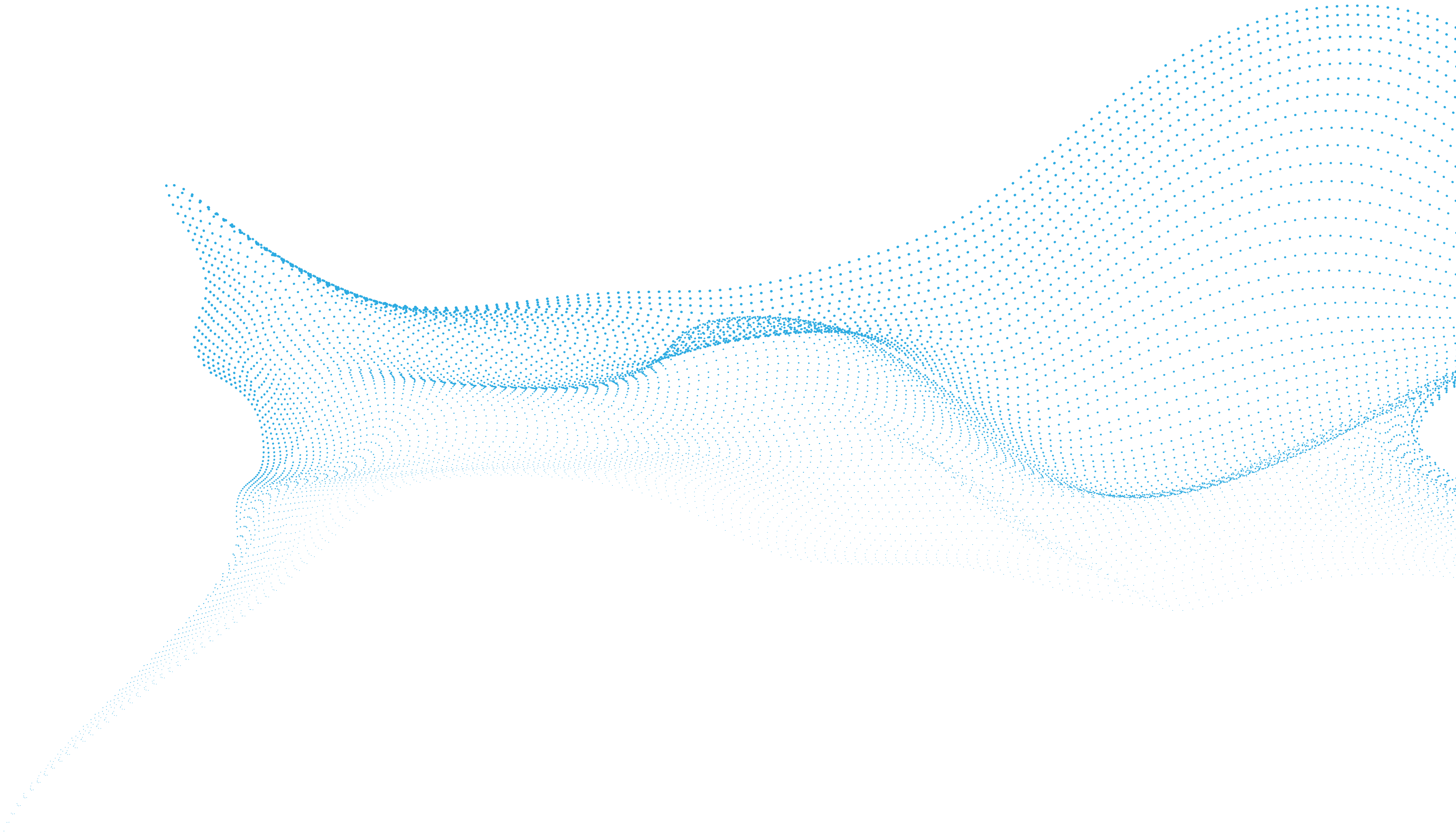
- the number of lived experience experts you want to engage
- the number of meetings and duration of work anticipated (remembering that lived experience experts need time to prepare for meetings)
- any dedicated work by the lived experience expert team (e.g., focus groups, priority-setting activities)
- costs of attending stakeholder meetings
- translation time with the lived experience experts (e.g., developing patient-facing documents)
- a person to support development of a sustainable model (enabling long-term relationships and engagement with lived experience experts so that they can be involved consistently in ongoing work)
- the costs of supporting lived experience experts to attend scientific meetings for presentation and dissemination of study results. These costs may include travel, accommodation and registration
- interpreters, accessibility aids and other forms of special assistance
- contingency funding (e.g., 10% of total budget) to allow for unexpected changes or delays.

2.3 Guiding Documents to Support the Process of Engagement

Supporting documents appropriate to the scope and nature of the project should be developed to guide engagement processes. Terms of Reference for lived experience expert advisory groups could include:

- overview; key terms and definitions; governance structure; membership eligibility and responsibility; onboarding processes; meeting frequency and content; communication strategy, including who will manage information requests; remuneration and reimbursement; resources and training; procedures for responding to distress lived experience experts might experience while undertaking engagement activities
- position descriptions (committee chair and members)
- how authorship will be managed on publications and grant applications

Universities and most hospitals now have lived experience expert engagement processes and ongoing relationships with lived experience experts. When engaging via a hospital, it is important to learn about and align with local processes, including police checks (required by hospitals), occupational health and safety procedures, and payment processes.



2.4 Ethical and Moral Considerations

Table 1 outlines the major ethical and moral considerations when undertaking PFE and the related practical considerations.

Table 1. Key ethical, moral and practical considerations in patient and family engagement

Factors	What needs to be considered?
Social and psychological support provision	The psychological safety of PWLE must be protected during and after engagement activities. Consider when it is appropriate to invite patients and families to participate in engagement activities, and identify aspects of their ICU or post-ICU experiences that are unwilling to discuss. Create a plan, with clear lines of responsibility, for responding to distress experienced as a result of engagement activities. Strategies may include offering debriefing, contacting the lived experience expert's general practitioner, and activating the organisation's employee assistance program. Distressed lived experience experts can also be referred to community-based resources, such as Lifeline, Lifeline Aotearoa, Beyond Blue, 13YARN, Mental Health Foundation of New Zealand
Selecting PWLE	Can the PWLE represent or access diverse, disadvantaged and/or marginalised communities (i.e., can they represent experiences, priorities and voices beyond their personal experience)?
How will relationships between PWLE and researchers be built or made stronger?	Trusting relationships are an essential foundation for power sharing, allowing PWLE to share the power traditionally held by researchers Mutual respect for different types of expertise is essential, and lived experience expertise should not be undervalued. Consider the use of first names in meetings and avoiding the use of titles on meeting agendas and other documents.
At the research priority-setting phase, who is leading/setting the scope?	Power is more likely to be shared when both partners and researchers can have input to health research topics. Funding and other constraints often obstruct power sharing, so it is essential to be transparent about scope – what can and cannot be the focus of the research, and why
Decision-making power	Will PWLE have equal decision-making power in the research group? Will they be collaborators or consultants? Who will make the final decisions?
Will PWLE be empowered as researchers?	Not all partners will want to participate as researchers, but if they wish to, support for their participation should be considered
When are PWLE involved?	Ideally, PWLE should be involved as early as possible, before the research priorities and questions are set
How many PWLE will be involved?	Projects often involve more researchers than PWLE, which skews the power imbalance further. Equal numbers are often unfeasible, and access to lived experience experts is difficult, but researchers should seek to recruit the optimal number of PWLE, with more representatives of marginalised groups
Space	Online facility access is very popular, but can hinder building relationships and deter PWLE from speaking up. Some more marginalised PWLE may lack access to online spaces/equipment If meeting in person, use a neutral space to enable partners to feel comfortable speaking up. If a community group is involved, meeting at their institution is ideal from a power sharing perspective. Meeting at a hospital site may be triggering for some PWLE

Factors	What needs to be considered?
Facilitation	Who facilitates engagement? What method of engagement will be used (e.g., focus groups or PWLE attending meetings)? How will the facilitation method allow partners to feel comfortable sharing relevant, personal stories? How will the facilitation method/approach give participants equal opportunity to speak? Co-facilitation models with a lived experience expert co-facilitator set the tone for power sharing and ensure the PWLE perspective is given equal priority
Listening	How will the research team ensure lived experience experts' ideas are listened to and acknowledged/discussed?
Being heard	Lived experience experts' and researchers' inputs should be treated equally, and the final research question/product should be decided jointly. If inputs from community partners are not included, justification should be given
Resources and compensation	See the subsection on Resourcing and Sustainability above
Unintended harms/risks	For lived experience experts: • potential for distress due to recall of traumatic events • more time away from work or other responsibilities than anticipated • burnout • disrespect from other lived experience experts during the process • reinforcement of stigmatisation of marginalised groups • disappointment due to unrealistic expectations about the anticipated outcomes of the research • disappointment due to poorly managed expectations and communication or lack of feedback on the outcome of involvement[11] For health professionals: • wounded pride and potential to feel threatened when hearing patients and families recount negative healthcare experiences • perceived irrelevance of lived experience expert engagement to their own work and negligible knowledge or new insights gained[11]) For organisations: • increased costs and use of resources (time and effort), resulting in apparent waste if improved outcomes are not achieved[11]
Accountability	How will the engagement process be evaluated? How will conflict resolution be managed?

2.5 Diversity of Engagement

Diversity should be considered when setting up PFE. Diversity, in essence, is recognising and combining differences to create unity among an entire community.[37] By increasing diversity, we create an inclusive, safe space where lived experience experts feel included, valued and respected. Moreover, a diverse group of lived experience experts in PFE can bring together different views and perspectives on how ICU research should be conducted and how health services can be delivered to all. While it can be nearly impossible to achieve representativeness, diversity of perspectives and engaging lived experience experts who are connected to PWLE networks invariably enriches research.

Researchers, clinicians and project managers should endeavour to ensure that:

- all PWLE who are interested in PFE are acknowledged and valued for their differences
- all PWLE are welcomed, supported and respected when undertaking PFE
- all PWLE are given equal opportunity to contribute and are not at a disadvantage due to their differences.

It is important to note that without canvassing lived experience, it can be difficult to know the views and needs of those who are disadvantaged, less influential, and marginalised; they should be actively sought and diverse perspectives included wherever possible. To increase the diversity of the lived experience expert group, researchers and clinicians may consider reaching out to leaders of communities, organisations that advocate for marginalised groups, and government agencies. In addition, it is necessary to culturally adapt and/or translate any information and resources to accommodate a wider audience of PWLE. More information on engaging diverse groups of PWLE can be found in Section 5.

2.6 Legislative and Policy Documents that Underpin Lived experience expert Engagement

It is important for researchers and lived experience experts to be familiar with legislative and policy documents that guide lived experience expert engagement in health and research. In Australia, these include the:

- *Australian Code for the Responsible Conduct of Research 2018*[38]
- *National Statement on Ethical Conduct in Human Research 2023*[39]
- *Statement on and Community Involvement in Health and Medical Research*[18]
- Partnering with Consumers Standard[7]
- *National Clinical Trials Governance Framework and User Guide*[40]
- *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities*[33]
- *Keeping Research on Track II*[34]
- *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*[36]

In Aotearoa New Zealand, there is a legislative imperative to engage with Māori, the tangata whenua (indigenous people), in health research. This is outlined in Te Tiriti o Waitangi, a foundational document that describes the partnership agreement between Māori and the Crown, in which Māori retain their tino rangatiratanga (sovereignty/self-determination).[41] Māori comprise 15.6% of all ICU admissions in Aotearoa New Zealand, so any research conducted in an ICU will include Māori patients and therefore will be required to engage with Māori communities at all stages.[42]

Lived experience expert engagement in health care settings is underpinned by four legislative documents: Te Tiriti o Waitangi (the Treaty of Waitangi), the Code of Health and Disability Services Consumers' Rights (the Code), the New Zealand Public Health and Disability Act 2000 and the Pae Ora (Healthy Futures) Act 2022 (1,10–13).[41,43-46] Further details about these documents are available in Appendix A.2.

Best Practice Points

Induction. Discuss and agree on how the engagement will work, what the lived experience experts will contribute, ensuring power sharing in this process. Induction can be supported by the ANZICS Introduction pack (Appendix E.1). This includes a welcome letter, position description, engagement contract, confidentiality agreement, remuneration agreement, log of hours, expense claim form, and expression of interest form.

Check in regularly (annually or bi-annually) with lived experience experts to see if they are still keen/able to partake in engagement activities. This may include bidirectional feedback between the researcher and lived experience experts about what is working well and what needs to be improved. Consider introducing a transition process for lived experience experts who wish to leave a project (e.g., a handover to an incoming lived experience experts). This may reduce any feelings of guilt or abandonment about needing to leave a project.

Use language that is easy to understand. Researchers should use lay language (avoid academic jargon and define abbreviations) when holding discussions and meetings with lived experience experts so that everyone has an equal understanding. This helps to increase confidence, trust and respect between researchers and lived experience experts.

Be realistic about timelines and involvement. Set out a realistic timeline for tasks to be progressed. Communicate regularly via email/telephone between meetings.

Maintenance of privacy, confidentiality and psychological safety. Lived experience experts should be supported to feel safe to share their experiences and insights (especially because accounts of their experiences in the ICU may be traumatic). Lived experience experts should be given the choice of anonymity or confidentiality in disclosure of personal experiences and should maintain the confidentiality of other lived experience experts involved.

Create a plan, with clear lines of responsibility, for responding to distress experienced as a result of engagement activities.

Remuneration. Reimburse lived experience experts for any out-of-pocket expenses related to engagement activities and remunerate them for their time. However, some lived experience experts may prefer not to be reimbursed and/or remunerated for altruistic reasons. These preferences should be discussed as part of the induction process to the project and revisited periodically. Seek local jurisdictional and organisational guidance on appropriate reimbursement and remuneration. Lived experience experts should be encouraged to seek independent advice about the implications of remuneration for tax or social security payments.

Acknowledge contributions regularly. Across all stages of research, it is important to acknowledge the considerable and meaningful PFE contributions by regularly reaching out to lived experience experts, making sure they do not feel overwhelmed by tasks, and reassuring them that the researchers will support them as much as possible. By not maintaining this relationship consistently, the purpose may be seen as tokenistic and transactional rather than meaningful, trusting and collaborative.

Follow legislative and policy guidance. When undertaking engagement work in Australia and Aotearoa New Zealand, be aware of the key national legislative and policy documents that underpin it.

SECTION

3

Guiding Principles for Patient and Family Engagement in Critical Care Research and Registries

> **ICU researchers who are really excited about having lived experience experts alongside them … take the time to explain all parts of the project. … They let me ask many questions … until I have a complete understanding. Because they made these investments in me, they get the following outcomes: a relationship for the future; a consumer with growing knowledge about ICU; a willingness to go through many failed applications; another person with ideas and innovation; a person who is regularly [in contact] with patients [and health services] who will push translation of research into practice; somebody who is willing to go the extra mile.**
>
> Former ICU patient and lived experience representative

Involvement of people with lived experience has been shown to improve the relevance, design, trust, transparency and impact of clinical trials and clinical quality registries (CQRs).[47,48] Recommendations for amplified patient and family engagement in CQR governance,[49] coupled with the requirement for structured inclusion by large-scale funding schemes,[18,50] have driven Australian initiatives to enhance approaches to support PFE.[51,52]

This guidance is intended to promote the highest standards of PFE in critical care research and CQRs while acknowledging the practical realities of diverse contexts. Guidance is provided for the clinical research context as well as registries, and has been written to align with the relevant ACSQHC clinical trials and CQR frameworks.[8,40] Recognising that the most advanced forms of PFE may not be feasible or appropriate in all cases, the researcher or CQR custodian is encouraged to identify the most appropriate engagement approaches that align with the desired level of involvement.[20] Two checklists outlining opportunities for PFE—one for each of clinical research and registries—are provided in Appendices B.1 and B.2 to support this process.

3.1 Partnering for Research

This section covers the planning, design, conduct, interpretation and dissemination of research involving PFE. It concludes with best practice points.

Planning

Effective and meaningful PFE begins with thoughtful, early planning. Ideally, engagement should commence during the research planning phase, allowing it to help shape the research agenda and identify priority healthcare issues from the outset. Early involvement ensures that research is grounded in lived experience and aligned with the needs of patients, families, and caregivers.

Engagement strategies may include partnering with established consumer networks, facilitating co-design workshops or focus groups, and gathering feedback from service user groups. These approaches help build trust, foster collaboration, and ensure that contributions are meaningful and sustained.

Structured approaches to research prioritisation, such as the James Lind Alliance Priority Setting Partnership, can be used to co-develop research questions that reflect the real-world needs of patients, families, and caregivers,[48,53] rather than assumptions made by clinicians or researchers.[54] These methods help ensure that research is grounded in lived experience and community relevance.

Lived experience experts should also be represented in funding applications, both as contributors to the proposal development process and as named collaborators or co-investigators where appropriate. This not only acknowledges their expertise but ensures that their involvement is resourced and recognised from the outset.

Once research priorities are established, lived experience experts can be engaged across the remaining five stages of the research—Planning, Design, Conduct, Interpret and Disseminate—each offering distinct opportunities for partnership and impact.

Design

Patient and family engagement during the design phase of research has been demonstrated to enhance design components—more user-focused research objectives, improved recruitment strategies, and the development of tools and materials that are more accessible and meaningful to participants.[55] Researchers are encouraged to consider how lived experience experts can contribute to the design of their study through one or more components (Table 2).

Challenges that may be encountered during the design stage include unclear roles, time constraints, low familiarity with research processes, and remuneration. Setting clear expectations and using existing resources to support these conversations, offering orientation or training to both PWLEs and researchers, using flexible, inclusive engagement strategies that accommodate different needs and capacities, and seeking funding for remuneration through local and national granting bodies can help overcome these challenges.

Table 2. Opportunities for involvement of lived experience experts during the research design process

Design component	Opportunity for contribution by lived experience experts
Shaping the research focus	Co-design research questions and objectives to reflect issues that matter to patients and families Help define eligibility criteria to better represent real-world diversity
Prioritising what matters	Select or develop outcome measures that prioritise patient-centred outcomes such as quality of life, functional status or caregiver burden
Ethical and inclusive design	Contribute to the design of consent materials and processes Ensure materials are clear, inclusive and culturally appropriate
Participant-centred recruitment and data collection	Tailor recruitment strategies to reflect participant perspectives Advise on data collection methods to maximise feasibility and acceptability Advise on strategies to reach hard-to-reach populations Contribute to data collection as members of the research team or a reference group. This can be especially helpful in interviews and focus groups, but should also be considered in quantitative research
Communication and feedback	Guide how and when results are communicated to participants Help establish feedback loops and decision-making pathways to ensure meaningful involvement

Conduct

Embedding PFE in the conduct of research has several potential benefits, including boosting recruitment, identifying ethical concerns and promoting transparency. Inclusion of lived experience experts on advisory panels helps ensure that research is ethically sound and aligns with community values and expectations. Improved engagement with lived experience experts can mean research outcomes are better understood and are more effectively implemented in healthcare. This includes strengthened community trust, leading to better participant recruitment, retention and follow-up, more culturally and/or linguistically appropriate engagement strategies, and greater inclusion of marginalised, disenfranchised or vulnerable groups. These benefits can be realised through various approaches, depending on the design of the study and preferences of the lived experience experts working with the research team:

- providing real-time feedback on factors influencing participant recruitment, consenting, and/or retention
- providing ongoing representation on steering committees, study management teams, and other governance groups to ensure best practice approaches are followed, such as including multiple lived experience experts in the group and implementation of adequate psychological support structures and remuneration
- leadership of lived experience expert advisory groups, including promoting membership, activities and reporting to research governance bodies.
- encouraging and enabling lived experience expert-led sub-studies on priority aspects of the research, such as decision-making during ICU admission, communication with families, or post-discharge recovery
- acting as co-facilitators or peer supporters within the ICU research environment, including during participant recruitment or consent discussions[56]
- supporting participant retention initiatives by helping to create flexible and responsive follow-up strategies
- co-developing and reviewing communications for explaining protocol amendments or study progress

Interpret

Patient and family engagement in data interpretation is increasingly recognised as one of the benefits arising from embedding lived experience experts as co-researchers, analysts and validators.[57] Lived experience experts in critical care can provide unique perspectives that challenge researchers' assumptions, enhance the depth and relevance of findings, and provide oversight and practical insights across qualitative and quantitative methodologies.[58,59] The benefits and impact of such involvement can be broad, including:

- ensuring that the findings are meaningful and actionable for patients, caregivers, and communities
- reporting findings within a strengths-based approach[60]
- ensuring findings are respectful and inclusive of minority and vulnerable groups
- highlighting ethical, cultural or contextual factors that influence the interpretation of data
- identifying and mitigating potential societal stigmas in data interpretation
- aligning results with patient and community expectation
- exploring and explaining unexpected or unusual findings

Lived experience experts can engage with data interpretation and analysis in many ways, depending on the research question and methodology (Table 3). For qualitative approaches, lived experience experts can be involved in qualitative data interpretation at various levels, including consultation, development, application, or a combination of these.[61] When using quantitative methodology, involvement of lived experience experts in research may add critical context to numerical data, and guide variable selection and model building.[59]

Table 3. Opportunities for PFE in qualitative and quantitative data interpretation

Qualitative Methodology	Quantitative Methodology
Consultative. Researchers present findings for feedback from lived experience experts **Development.** Lived experience experts co-create coding frameworks or themes **Application.** Lived experience experts apply themes to data **Combination.** Extensive collaboration in which lived experience experts are involved throughout the entire analysis process	**Consultative.** Lived experience experts help refine research instruments or review data interpretations **Collaborative.** Direct involvement of lived experience experts in determining data collection methods, variables and model assumptions, and collecting data

Consideration should be given to the needs of lived experience experts in data interpretation (Table 4). This includes training lived experience experts to develop the skills needed for data interpretation and analysis, as well as balancing expectations and workloads to ensure successful collaboration.

Table 4. Key points to consider for lived experience experts involved in data analysis

Area of focus	Considerations
Statistical complexity	Advanced data analysis may limit involvement of lived experience experts due to statistical complexity. Participatory modelling provides a way to incorporate lay knowledge effectively. Ensuring diversity while minimising participant bias remains an ongoing concern[59]
Health and functional status	The health and functional status of lived experience experts may reduce their ability to engage in extensive collaboration. Adjustments should be made to collaboration strategies based on ongoing feedback from lived experience experts
Clear articulation of involvement	The level of involvement of lived experience experts in data interpretation should be defined clearly in the terms of reference during the planning phase. This should also be reflected in the methods section and discussed in the resulting manuscript
Managing diverging opinions	Areas where differing opinions arise (whether between researchers and/or lived experience experts) should be reported. Understanding the nature of these disagreements—whether between individual lived experience experts or between researchers and lived experience experts—is just as valuable as understanding areas of agreement

Disseminate

Involving lived experience experts in the dissemination phase helps to ensure that research findings and outputs are communicated in ways that are meaningful, accessible and relevant to diverse audiences. Lived experience experts can help extend the reach of dissemination efforts beyond academic audiences to patients, families and the wider community, using a variety of forums (Table 5). By contributing to the interpretation of findings, lived experience experts help shape the messaging that resonates with end users and informs future research agendas. The involvement of lived experience experts in these activities should still be guided by their preferred level of involvement.[20]

Table 5. Opportunities for patient and family engagement in dissemination

Dissemination strategy	Lived experience expert involvement	Modality
Academic publications	Co-authoring papers, reviewing drafts for clarity and relevance	Peer-reviewed journals
Conference presentations	Co-presenting findings, sharing lived experience perspectives	Scientific conferences, workshops, webinars
Lay summaries and infographics	Co-developing or reviewing materials to ensure accessibility	Fact sheets, infographics, websites
Community outreach	Sharing findings through networks, hosting community information sessions	Community forums, patient advocacy groups
Media engagement	Participating in interviews, contributing to opinion pieces	Traditional media (TV, newspapers), social media
Implementation tools	Advising on or co-creating decision aids and patient resources	Clinical guidelines, patient information leaflets

Researchers should use best-practice tools—namely, GRIPP2[27]—to transparently report how lived experience experts were involved throughout the research, including dissemination activities.

As in other aspects of research, it is important to recognise challenges associated with these activities and be solution focused. Challenges may include lived experience experts' limited experience with scientific communication, uncertainty about roles, and lack of access to traditional dissemination platforms. To overcome them, researchers can offer training and mentorship on academic writing and public speaking, define expectations early, and create diverse dissemination pathways that value both academic and community-facing outputs. Providing support for travel, presentation preparation and media engagement, and recognising contributions through authorship and acknowledgement, can help create an inclusive and empowering environment.

✓ Best Practice Points

Patient and family engagement in clinical research can occur across the research lifecycle: planning, design, conduct, interpretation and dissemination.

Research planning. Ideally, begin engagement in the planning phase. Strategies include co-design workshops or focus groups, gathering feedback from service user groups, or structured approaches to research prioritisation and question development, such as the James Lind Alliance Priority Setting Partnership. Represent lived experience experts in funding applications to recognise their contribution and ensure their involvement is resourced.

Research design. Lived experience experts can co-design research questions, define eligibility criteria, select or develop patient-centred outcome measures, guide data collection methods to ensure acceptability and feasibility, co-design consent materials and processes and tailor recruitment strategies, and guide how results are communicated to participants.

Research conduct. Include lived experience experts on advisory panels, steering committees, study management teams and other governance groups. Work with lived experience experts to co-design improved participant retention initiatives and co-develop communications about study progress. Encourage lived experience expert-led substudies on aspects of the research and co-data collection.

Research interpretation. Lived experience experts can engage with data interpretation and analysis in many ways, depending on the research methodology. Lived experience experts can be involved in qualitative data interpretation at various levels, including consultation, development, application, or a combination. Involvement of lived experience experts in quantitative research may add critical context to numerical data, and guide variable selection and model building. Lived experience experts can ensure findings are meaningful and actionable for patients and communities and they can partner with researchers to explore unexpected or unusual findings.

Research dissemination. Lived experience experts can ensure that research outputs are communicated in ways that are meaningful and accessible to diverse audiences. Opportunities for PFE in dissemination include academic publications, conference presentations, lay summaries and infographics, community outreach, media engagement and advising on implementation tools. Lived experience experts can also be involved in research translation and advocacy for research results.

3.2 Additional Considerations for Clinical Quality Registries

While the principles outlined throughout this document apply broadly to both research and registry contexts, CQRs present unique opportunities and challenges for PFE. Although there is currently less published evidence on the benefits of PFE in CQRs,[12] emerging guidance strongly supports their inclusion in registry design, governance, and interpretation.[62] Many of the strategies described earlier in this section—such as co-design, inclusive governance, and meaningful dissemination—remain highly relevant and should be adapted to the registry setting. However, CQRs also require specific considerations due to their ongoing, data-driven nature and their role in monitoring and improving healthcare quality over time.

To ensure that CQRs remain relevant, ethical, and responsive to community needs, PFE should be embedded in key aspects of registry operations, including governance, indicator selection, data interpretation, and equity considerations (Table 6).

Table 6. Opportunities for patient and family engagement in clinical quality registry activities

Registry consideration	Lived experience expert contribution
Governance and oversight	Include lived experience experts in advisory panels and governance structures to ensure ethical oversight and alignment with community values Maintain ongoing engagement to support transparency and accountability
Indicator selection	Involve lived experience experts in selecting and reviewing registry indicators to ensure data collected is meaningful, actionable and patient-centred
Data interpretation	Engage lived experience experts in interpreting registry data, including through advisory groups or ad hoc projects, to provide context and challenge assumptions
Patient and family-reported measures	Include lived experience experts in the development and oversight of patient-reported outcome/experience measures to ensure they reflect what matters most to patients and families
Equity and representation	Ensure representation of vulnerable and priority populations, including Māori, Aboriginal and Torres Strait Islander peoples Respect Indigenous data sovereignty in the collection and use of routinely gathered data

Best Practice Point

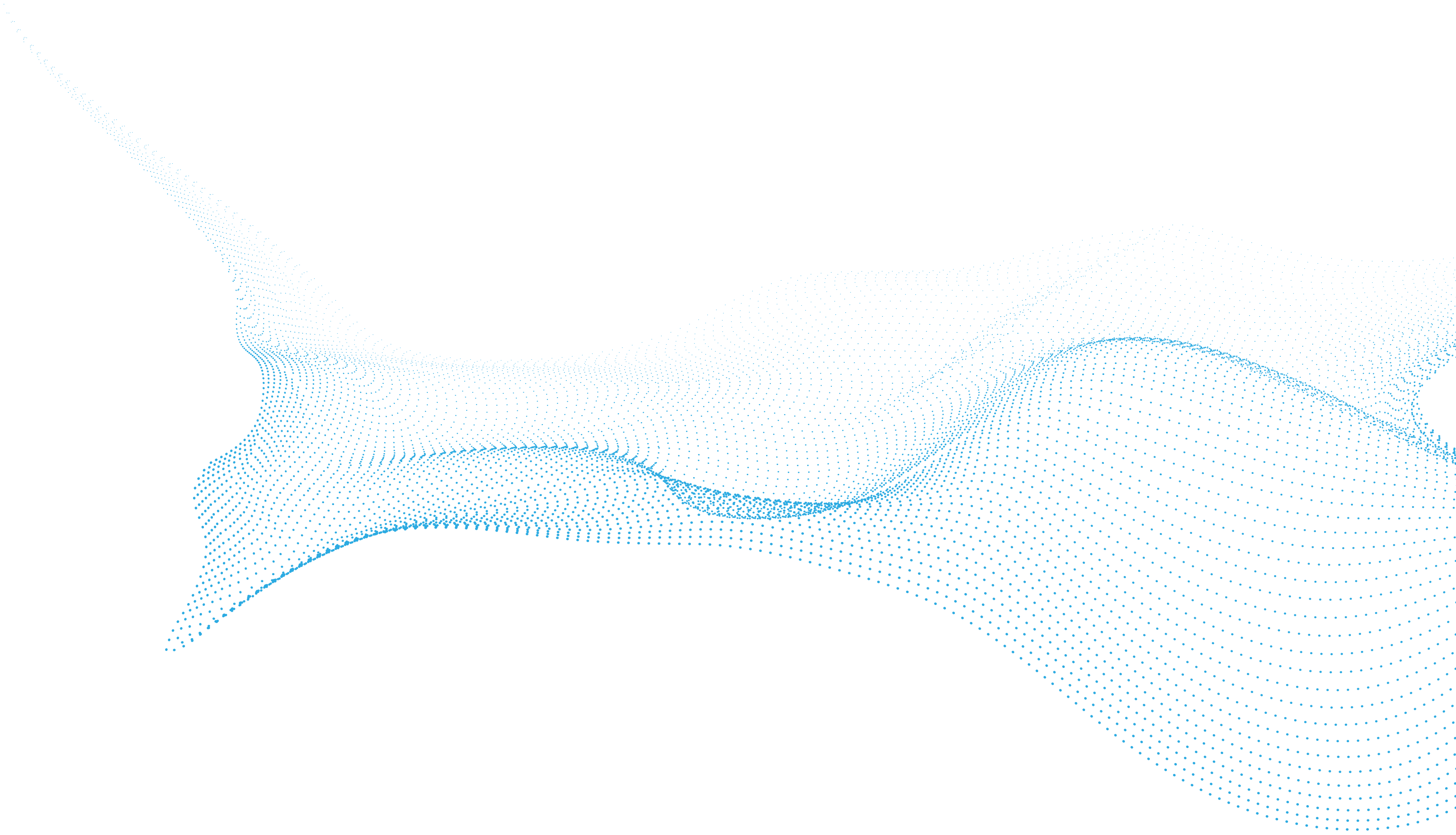
To ensure that CQRs remain relevant, ethical and responsive to community needs, PFE should be embedded in key aspects of registry operations, including governance (inclusion of lived experience experts on advisory panels and governance structures), indicator selection, data interpretation, development and oversight of patient-reported outcome and experience measures, and equity considerations (ensure representation of vulnerable and priority populations, respect Indigenous data sovereignty).

3.3 Additional Considerations for Paediatric Studies and Registries

Involving PWLE in paediatric studies is more complex than in adult contexts. PWLE for these studies can include parents, carers, children and young people admitted to an ICU, their siblings, and extended family such as grandparents. Schools and community groups can also be engaged. Engaging with this diverse group, in particular children and young people, requires some specific strategies.

- Parental or guardian support for children to contribute as PWLE, as well as child assent, is required.
- Age-appropriate communications and explanations are essential, including the use of diverse approaches (see Appendix D.3).
- Flexible scheduling should be incorporated to accommodate school and family commitments, and the cognitive and emotional load on children must be considered and accommodated.
- Ethical considerations are vital, and researchers with appropriate clinical and/or research backgrounds must be involved in exchanges with the children, as well as supporting the family after the engagement activity.

Detailed considerations for engagement with children and young people appear in Section 5.



SECTION

4

Measuring the Impact of Patient and Family Engagement

> **There isn't one 'right way' to evaluate consumer engagement. There are many tools, frameworks and approaches available. If there isn't a suitable approach, don't be afraid to develop your own.**
>
> Former ICU patient and lived experience representative

Global guidelines and national public health policies emphasise the importance of engaging PWLE in the research process,[18,63] and how PWLE do so continues to evolve. While much is known about the frameworks to support this type of engagement,[64] less is known about how to measure the impact when PWLE engage in research.[65]

4.1 What is impact?

In this context, impact can be defined as the difference that involvement of PWLE make to the research, whether on those involved in the research (researchers, partners, broader community) or the research process itself.[65] Consequently, the outcomes to be considered when measuring the impact of engaging PWLE in research vary considerably and are context dependent.

Evidence of impact

Engaging PWLE in the research process can increase respect and trust among stakeholders and increase confidence in and satisfaction with engagement. Outcomes will be somewhat dependent on the diversity of lived experience experts engaged and the degree of engagement with the research.[66] Several systematic or scoping reviews of the impact of research engagement have been undertaken,[65,66] many from the United Kingdom,[67,68] where the concept of public and patient involvement in research is well established. Impacts are broadly grouped conceptually by the research process, the participants, the researchers and society/ wider community. While not an exhaustive list, measurable outcomes are listed in Table 7.[65]

Table 7. Impact of engaging people with lived experience in research

Concept	Impacts
Research process	• The research agenda and priority • Research relevance • Quality research design and delivery, outcome measures, time and costs • Participant recruitment and retention • Research ethics • Transparency of research activities • Interpretation of results
People with lived experience	• New skills and knowledge • Personal development • Support and friendship • Enjoyment and satisfaction • Empowerment • Financial reward • Improved individual health or care
Researchers	• Knowledge and understanding of the community • Enjoyment and satisfaction • Career benefits
Organisation	• Trust and acceptance of research • Improved relationships with community • New and improved services/practice changes • Capacity building
Society/wider community	• Greater trust and acceptance of research • Translation and dissemination of research findings • Culture change • Improved relationships with professionals/research organisation • Translation and dissemination of research findings • New and improved services/practice changes • Culture change • Capacity building

✓ **Top tip** In the initial stages the team should meet to identify the impacts of engaging PWLE that are most important to the research and those involved.

Assessing impact

Many tools can guide evaluation of research impact when PWLE are engaged in research. Some of the more prominent tools are listed in Appendix C.

Some guiding principles for assessing impact are listed below.

- Build evaluation throughout the project and adjust the process as needed. Routinely capture impacts that occur in discussions between the researchers and PWLE to enable reporting of impacts of co-production.
- Use a collaborative approach in the research design phase to discuss and identify evaluation targets. Consider impacts from multiple perspectives, including the participants, researchers, organisation and broader community.
- Design your research impact evaluation to be proportionate to the study size and the extent to which involvement of PWLE is incorporated into your research. Consider the costs and benefits.
- Use an available evaluation tool, adapt an existing tool, or build your own. There are many ways to approach evaluation, and it should be tailored to your study.
- Engage all stakeholders—multiple perspectives help ensure a more robust evaluation.
- Regularly ask your lived experience experts what is going well and what aspects could be done better.
- Collaborate on the writing of evaluation reports to ensure PWLE can contribute and check that the report is congruent with their experience.
- Appropriately acknowledge and identify PWLE in any reports to promote transparency.
- Share the results of your evaluation to support learning by your team and others.
- Capture both positive and negative impacts in your evaluation.

If you decide to use an existing tool, Table 8 lists questions you could ask to help identify the best fit for your study.

Table 8. Questions to guide evaluation tool selection

Concept	Question
Quality and scope	Is the nature and quality of lived experience expert engagement in the research assessed? Does the tool evaluate the extent to which the engagement is authentic?
Impact on the research process	Does the tool assess PWLE involvement in all aspects of the research project?
Impact on research outputs and outcomes	Does the tool assess the impact on study processes (e.g., recruitment) as well as longer term outcomes such as health and economic impact?
Evaluation perspective	Is the impact of PWLE engagement considered from multiple perspectives including those of the lived experience expert, researcher, organisation and funder?
Goodness of fit	Does the tool fit the type of research being conducted?
Types of evaluation data	Does the tool allow for collection of both quantitative data to review trends over time and qualitative data that facilitate a deeper understanding of involvement?
Ease of use	Is a special skill set required to use the tool? Does it require additional time and funding?

Challenges of measuring impact

It is often difficult to measure impact because it is hard to identify the effects of individual contributions. Across studies, contexts differ and involvement may result in disparate impacts. It is also important to recognise that not all important impacts are easily measurable, thus making them more difficult to evaluate.[69] In some situations, narrative style case studies can be used to convey the 'story' behind the impact, which can help build on the more traditional quantitative metrics. However, this approach also has limitations, in that it can be difficult to demonstrate a relationship between the research engagement and the impact outcomes observed.[70]

✓ **Top tip** Assess both positive and negative research engagement impact to avoid positive bias.

4.2 Reporting the involvement of people with lived experience

Reporting the involvement of people with lived experience in the research process helps to improve the quality, transparency and consistency of the evidence base. The current GRIPP2 identifies the need for both a long and short form version of the reporting guidelines.[27] The long form contains 34 items and is intended to be used when lived experience expert involvement is the primary focus of the research, noting that researchers select the items of relevance in their reporting. The short form is a simplified version that contains 5 items to be reported against each key stage of the research process—aim, methods, study results, discussion/conclusion, reflection/critical perspective. The GRIPP2-SF is used when lived experience expert engagement has a more secondary purpose.

In addition to reporting the methods, extent and impact of patient and family engagement, it is also important to report who was engaged. This includes describing the number and demographics of patients, family and the public who were involved with the engagement activity in the research.

The modified GRIPP2[71] was developed to better describe multistakeholder involvement practices in a working group. The authors recommend reflecting on what has been learnt about co-production and the impact on the research. Suggested questions are listed below.

- What was your overall experience of being part of the research team?
- What influence did you have on the review? Can you give examples?
- What influence did being involved in the working group have on you and/or your work?
- Was there anything about the working group that could have been improved, and if so, what?

✓ **Best Practice Points**

In the initial stages the team should meet to identify the impacts of engaging people with lived experience that are most important to the research and those involved.

Assess both positive and negative research engagement impacts to avoid positive bias.

Researchers and PWLE can modify existing tools to ensure that they assess the most important impacts of their study.

Plan reporting of involvement of PWLE in each of the outputs associated with your research.

SECTION

5

Applying the Principles of Engagement in Partnership with Diverse Groups

> **The Aboriginal Liaison Team provided the much-needed cultural support and assistance we desperately required. Without their knowledge, understanding and active participation we, as a family, would not have felt culturally safe or empowered to journey the traumatic period we unfortunately had to undertake with our beloved son. The Team uplifted us in their timely ability to go above and beyond to support us, not only with various information about accommodation, transportation and the like, but taking the time to sit and 'yarn' with us as we waited.**
>
> ICU caregiver and lived experience representative

This section focuses on engagement with patients and family members with diverse backgrounds and unique needs. We provide key considerations for PFE with diverse population groups and resources to support enhanced communication and ensure ethical and person-centred approaches. Consistent with the broader principles of PFE, a patient and family-centered approach to engagement is essential.[72]

Approaches to patient and family-centred care in the ICU research environment mirror those applied in clinical care, prioritising the needs, values and preferences of survivors of critical illness and their families.[73] The key elements are:

- respect for patient and family preferences
- shared decision making
- effective communication and transparency
- emotional and psychological support
- family involvement and presence
- comfort and dignity and continuity of care[74]

Applying these principles helps research conducted for or with ICU survivors to align with what matters most to patients and their loved ones.

In this section we focus on key population groups whose needs may vary significantly from what was once considered the 'average' ICU patient or family member involved in research. We use the term 'average' respectfully, to acknowledge that ICU research has historically reflected colonial and patriarchal structures,[75] shaping everything from who received care to whose voices were valued in research. While progress has been made, decolonising and diversifying ICU research remains an ongoing challenge. The following subsections concentrate on key population groups whose characteristics must be considered when undertaking PFE activities in Australia and Aotearoa New Zealand.

5.1 Aboriginal and Torres Strait Islander Australians

The longstanding impacts of colonisation

Aboriginal and Torres Strait Islander peoples have been living in the land we call Australia for at least 65,000 years.[76,77] Before colonisation, Aboriginal and Torres Strait Islander peoples experienced strong social and emotional wellbeing, rooted in deep connections to Country, spirituality, family and culture. British colonisation disrupted these systems. Colonial policies, including the forced removal of children from their families and communities, have caused substantial intergenerational trauma, contributing to persistent disparities in health outcomes and hindering the ability of Aboriginal and Torres Strait Islander communities to maintain and practice their holistic models of health.[22,79,80]

The legacy of the historical and continued injustices that continue to affect Aboriginal and Torres Strait Islander peoples today[80] must be considered in all engagement, including for research. It creates significant challenges for building trust and sharing of lived experience perspectives. Acknowledging and working to overcome these structural and systemic impacts is essential for ethical, culturally safe, and effective research.

Definition of health and wellbeing

For Aboriginal and Torres Strait Islander peoples, health and wellbeing extend far beyond the absence of disease.[81] Health is viewed holistically, encompassing physical, social, emotional, cultural and spiritual dimensions, both for the individual and communities. This perspective is interconnected and recognises how social, cultural, historical and environmental factors, and connection to Country, influence wellbeing.[82]

Terms such as 'social and emotional wellbeing' have emerged to better reflect these unique and holistic concepts of health.[22] Aboriginal Community Controlled Health Organisations, established in the 1970s, were instrumental in formalising this approach. In 1979, the National Aboriginal and Islander Health Organisation (now NACCHO) defined Aboriginal health as a concept concerned with the wellbeing of the whole community, not just the physical health of individuals. This foundational understanding was later integrated into Australia's first National Aboriginal Health Strategy.[82]

Definitions of wellbeing can vary across communities. The linguistic and cultural diversity of Aboriginal and Torres Strait Islander peoples must be acknowledged, because these differences shape how health, mental health, and healing are understood and experienced.[83]

Cultural determinants of health

The cultural determinants of health refer to the foundational strengths that empower individuals, families and communities. For Aboriginal and Torres Strait Islander peoples, they include connection to culture, language, Country, community, family and spirituality. These determinants are central to wellbeing and act as protective factors that foster resilience, identity and healing.[35,80,84]

While dominant paradigms in health research have traditionally framed Aboriginal and Torres Strait Islander health using a deficit narrative that emphasises socioeconomic disadvantage, there is now strong recognition of the importance of strengths-based, culturally grounded approaches. The cultural determinants of health framework is most closely aligned to Aboriginal and Torres Strait Islander peoples' definitions of health and wellbeing.[85]

Aboriginal and Torres Strait Islander engagement and leadership in research

Aboriginal and Torres Strait Islander peoples have the right to self-determination in all areas of life, including research. Historically, research has frequently excluded or exploited Indigenous communities, failing to respect the value of cultural practices or deliver meaningful outcomes. In response, Aboriginal and Torres Strait Islander peoples have developed ethical guidelines that affirm the right to define research priorities, lead research teams, and ensure culturally appropriate methods are used.[33,34,77]

Research is more successful and impactful when Aboriginal and Torres Strait Islander leaders including Elders, community members, researchers and academics are involved in its design, conduct and translation.[86] Aboriginal and Torres Strait Islander leadership ensures that research aligns with community priorities, reflects cultural values, and promotes equitable outcomes. Leadership also means that Aboriginal and Torres Strait Islander peoples are involved not just as participants but as authors, decision-makers and key knowledge holders at every stage of the research process.[87]

Data sovereignty & governance

Aboriginal and Torres Strait Islander peoples have the right to control how data about them is collected, used, stored, and shared.[34,65,88] Historically, research was done on rather than with Aboriginal and Torres Strait Islander peoples. Ethical research now requires that data reflect Indigenous worldviews, such as cultural determinants of health, to ensure research upholds the principles of self-determination as well as cultural values and community wellbeing.

Strong data governance means that data aligns with community needs and priorities, quality standards are culturally appropriate, and data is timely and accessible. In all research involving Aboriginal and Torres Strait Islander peoples, agreements should protect data sovereignty. These must cover:

- intellectual and cultural property rights
- data collection, storage, and access protocols
- roles, responsibilities, and accountability measures

Such agreements must be co-designed and endorsed by Aboriginal and Torres Strait Islander representatives to ensure trust and uphold sovereignty.

Effective engagement

Effective and meaningful engagement in research with Aboriginal and Torres Strait Islander peoples is underpinned by trust, reciprocity and respect for sovereignty. It requires researchers to:

- recognise and respect the rights of Aboriginal and Torres Strait Islander peoples to identify their own research priorities
- co-design research projects and methodologies with communities
- ensure free, prior and informed consent at all stages
- secure community support and involvement from inception to dissemination
- adequately resource and support Aboriginal and Torres Strait Islander leadership and participation[87]
- uphold principles of Indigenous data sovereignty and governance[35]
- be sensitive to and respectful of the significant cultural load and additional workload borne by Aboriginal and Torres Strait Islander people in the workplace, where they are either the only Aboriginal and/or Torres Strait Islander or one of a small number of Aboriginal and Torres Strait Islander people involved.[89]

Effective engagement is about ensuring Aboriginal and Torres Strait Islander peoples have control over research that affects them, shaping knowledge production in ways that support community wellbeing, cultural continuity, and self-determination.[87]

5.2 Māori

Māori perspectives on health and wellbeing: implications for engagement in research

For researchers to engage meaningfully with Māori patients, whānau and communities, it is essential that they understand Māori perspectives of health and how colonisation has shaped and suppressed Māori hauora (health and wellbeing) and Māori interactions with the health system.

Mason Durie described how the imposition of Western biomedical models of health has systematically harmed Māori wellbeing.[24] Not only did colonisation seek to erase Māori knowledge systems, it resulted in forced alienation from land, economic marginalisation, cultural assimilation, and the spread of deadly infectious diseases.[92] Additionally, the imposition of Western healthcare systems for Māori created further barriers of access, cost, and mistrust, exacerbating health inequities.[24,90] Colonisation is an ongoing process, and studies describing Māori experiences of the health system highlight experiences of racism, lack of cultural safety, poor awareness of Māori holistic health needs, and mistrust of health professionals as key barriers to care for Māori.[91,92]

This history is important, because it is the context in which Māori patients/whānau experience the healthcare system. Meaningful engagement with Māori in research can help to enhance Māori rangatiratanga (autonomy) and ensure that the research is working to minimise inequities.

What is the kaupapa?

Researchers must determine the kaupapa (topic/subject/study) in which they wish to engage Māori lived experience experts, then think about the appropriate level of involvement. In general, a kaupapa that has a greater impact on Māori should require more involvement from Māori communities (noting that any ICU study conducted in New Zealand is likely to involve Māori patients and thus require engagement). A guide to levels of engagement can be found in *Guidelines for Engagement With Māori.*[93]

Researchers should think about how their kaupapa might affect Māori and what steps are needed to make the study equitable and safe for these patients, then seek feedback from Māori lived experience experts. This indicates to lived experience experts that Māori health equity is a priority for the researchers.

Who to engage?

Māori community structures are built around concepts such as whakapapa, which describe ancestral and environmental connections to all things.[94] Through a Māori worldview, collective relationships and obligations are paramount; this creates a tension between Western perceptions of individual consent and Māori collective autonomy.[94] This concept of collective autonomy is important for researchers wanting to engage with Māori lived experience experts, because it may not be ethical (from a Māori perspective) to include individual patients without the consent and involvement of their wider whānau. Thus, researchers should create space for Māori lived experience experts and their whānau to be involved if preferred.

Furthermore, researchers should consider the geographical location of their research and consult with Māori communities within that area (see *Guidelines for Engagement With Māori*).[93] This is because each iwi and hapū (tribe/subtribe) have their own mana (autonomy), practices and tikanga (appropriate protocols), so what works for one iwi may not work for another. Researchers can contact the Māori Research Advisory Boards in each hospital for direction. Additionally, the contact details for each site's preferred Māori support staff are in patient information and consent forms.

How to engage?

It is important that researchers engage with Māori communities in a culturally safe way through whakawhanaungatanga (relationship building), manaakitanga (care/respect) and tikanga (appropriate protocols). The decolonisation work mentioned above is a critical first step for researchers and will help researchers to learn and understand Māori ways of being.

Three frameworks that can guide researchers and clinicians in their interactions with Māori patients and whānau are The Hui Process,[95] the Meihana model,[114] and Te Wheke.[96] Further details about these frameworks appear in Appendix D.

Additional things to consider:

- **Koha (gift):** how are you acknowledging the lived experience expert's time and energy?
- **Tikanga (appropriate protocols):** what protocols are relevant to ensure the interaction is culturally safe? This may include use of karakia (prayers or incantations), kai (food), not setting time limits on hui (meetings).
- How are you uplifting the **mana (power/autonomy)** of the lived experience experts involved? Are you enhancing Māori research capacity? How are you privileging Māori perspectives/aspirations in your research?

Māori Data sovereignty

Māori Data Sovereignty asserts the "inherent rights and interests that Māori have in relation to the collection, ownership, and application of Māori data.[97] This involves Māori having control over what data are collected, how they are used, where they are stored and the purposes they serve. Te Mana Raraunga (The Māori Data Sovereignty Network) has created a set of six key principles to guide the implementation of Māori Data Sovereignty: Rangatiratanga (Authority), Whakapapa (Relationships), Whanaungatanga (Obligations), Kotahitanga (Collective benefit), Manaakitanga (Reciprocity) and Kaitiakitanga (Guardianship).[97] These principles outline how Māori data should be protected and used in ways that enhance Māori wellbeing and aspirations of self-determination. According to Te Kāhui Raraunga (The Māori Data Governance Network), Māori data today refers to any 'digital or digitisable data, information or knowledge (including mātauranga Māori) that is about, from or connected to Māori. It includes data about population, place, culture and environment'.[98] These data are important parts of a broader cultural ecosystem and hold vast potential to advance equity and development for Māori communities.

The following resources provide guidance about how to uphold the principles of Māori Data Sovereignty:

- Te Mana Raraunga Māori Data Sovereignty Principles[97]
- Te Kāhui Raraunga Māori Data Governance Model[98]
- The CARE Principles for Indigenous Data Governance[99]
- National Ethics Advisory Committee guidelines[100]

Best Practice Points

Engaging with Aboriginal and Torres Strait Islander People: Effective engagement is about ensuring Aboriginal and Torres Strait Islander peoples have control over research that affects them, shaping knowledge production in ways that support community wellbeing, cultural continuity, and self-determination. Uphold principles of Indigenous data sovereignty and governance.

Engaging with Māori: For researchers to engage meaningfully with Māori patients, whānau and communities, it is essential they understand Māori perspectives of health and how colonisation has shaped and suppressed Māori hauora (health and wellbeing). Be guided by frameworks such as the Hui Process, the Meihana model and Te Wheke. Uphold principles of Māori data sovereignty and governance.

Other considerations when engaging with First Nations peoples: Recognise and respect First Nations rights to identify their own research priorities. Co-design research projects and methodologies with communities. Ensure free, prior, and informed consent by lived experience experts participating in any research engagement activities. Provide adequate resourcing and support for leadership and participation. Be sensitive and respectful of the significant cultural load borne by First Nations people. Uphold principles of Indigenous data sovereignty and governance.

5.3 Other Culturally and Linguistically Diverse Communities

In 2021, just over 7 million people living in Australia were born overseas, representing 27.6% of the population; this was an increase from 6.1 million, or 26.3%, in 2016.[101] The 2023 Census showed that people living in Aotearoa New Zealand identified with a wide range of ethnicities and spoke over 150 languages, with just under 30% born overseas in over 200 birthplaces.[102] Culturally and linguistically diverse (CALD) is a term used to describe those who were born overseas, have parents who were born overseas or speak languages other than the official national languages and/or have lower proficiency of native or national languages.[102] Inequities in engagement identified in these communities are compounded by fears of intimidation, low self-confidence in their own healthcare, racism, gender inequalities, sex, disabilities, low trust in health professionals and the health care system, and communication barriers.[103-106]

The following guide aims to assist researchers to effectively engage CALD communities/lived experience experts to strengthen the participatory processes in critical care research to achieve equitable outcomes (Figure 4).[107]

Step 1: Determine and communicate purpose

a. Set clear parameters for and identify the purpose of the engagement process
b. Create a communication strategy for the intent of the engagement (e.g., to improve service efficiency, acceptability, access and equity)
c. Ensure equal levels of power in the engagement

Step 2: Identify key communities and participants

a. Identify key groups/communities to be involved
b. Involve key community representatives and seek advice about best methods of engaging with communities
c. Ensure the engaged members include diverse views from the wider community/group of interest
d. Formulate strategies to build capacity to overcome the barriers experienced by multicultural communities

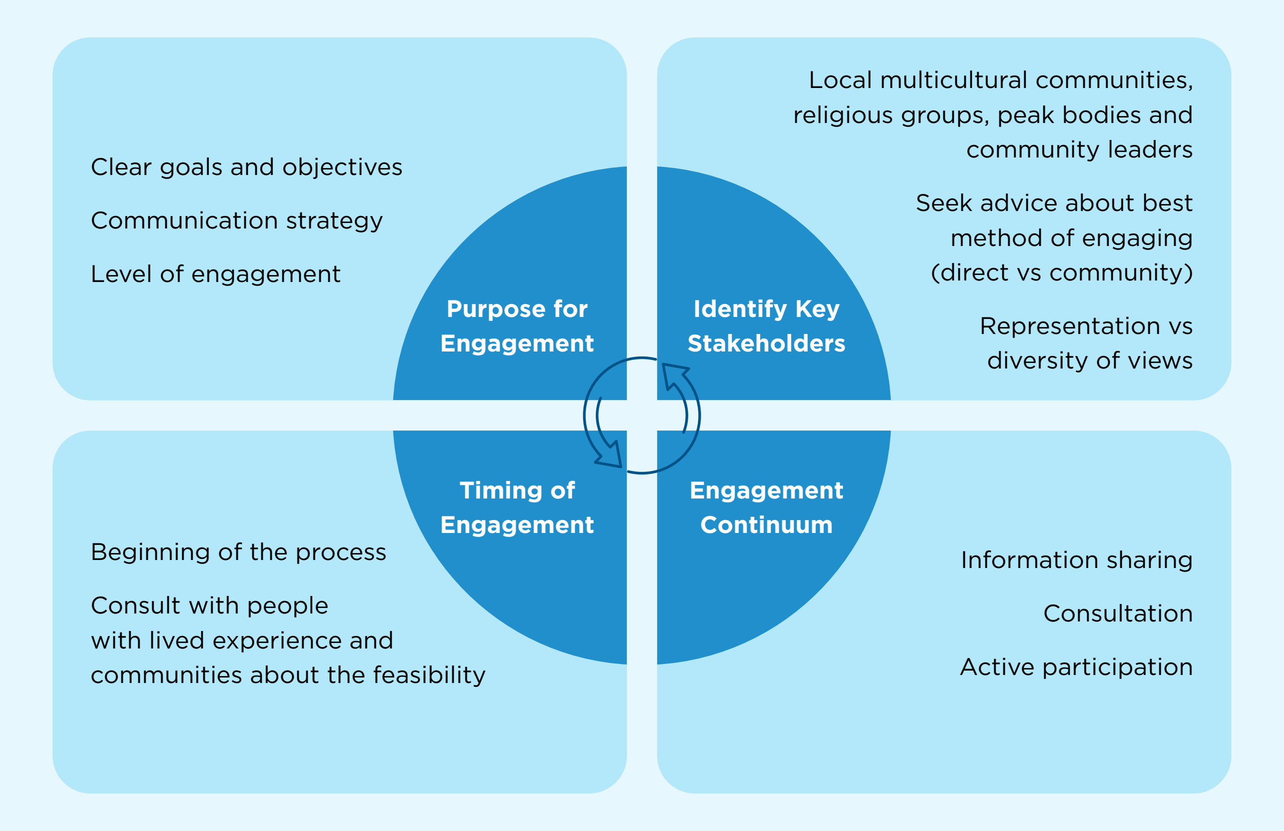
Step 3: Agree on feasibility and timing

a. Consult with lived experience experts/organisations about the feasibility of the engagement
b. Consult with lived experience experts/organisations about the timing of the engagement

Step 4: Develop strategies

a. Plan effective information sharing to develop ongoing relationships (e.g., using printed material, multicultural media)
b. Engage in lived experience expert consultation (e.g., via steering committees, advisory groups, focus groups)
c. Consider inviting multicultural lived experience experts onto the board of management

Figure 4. Strengthening engagement with people from CALD communities



Best Practice Point

Strengthening research with other CALD communities requires defining the purpose of engagement clearly, identifying key communities and participants, considering the feasibility and timing of engagement, and mapping out the engagement continuum.

5.4 Gender-Responsive Engagement in Research

Engaging respectfully with people of diverse gender identities requires inclusive, safe and equitable research practices. Gender responsiveness strengthens research quality and ensures all participants are valued and heard.

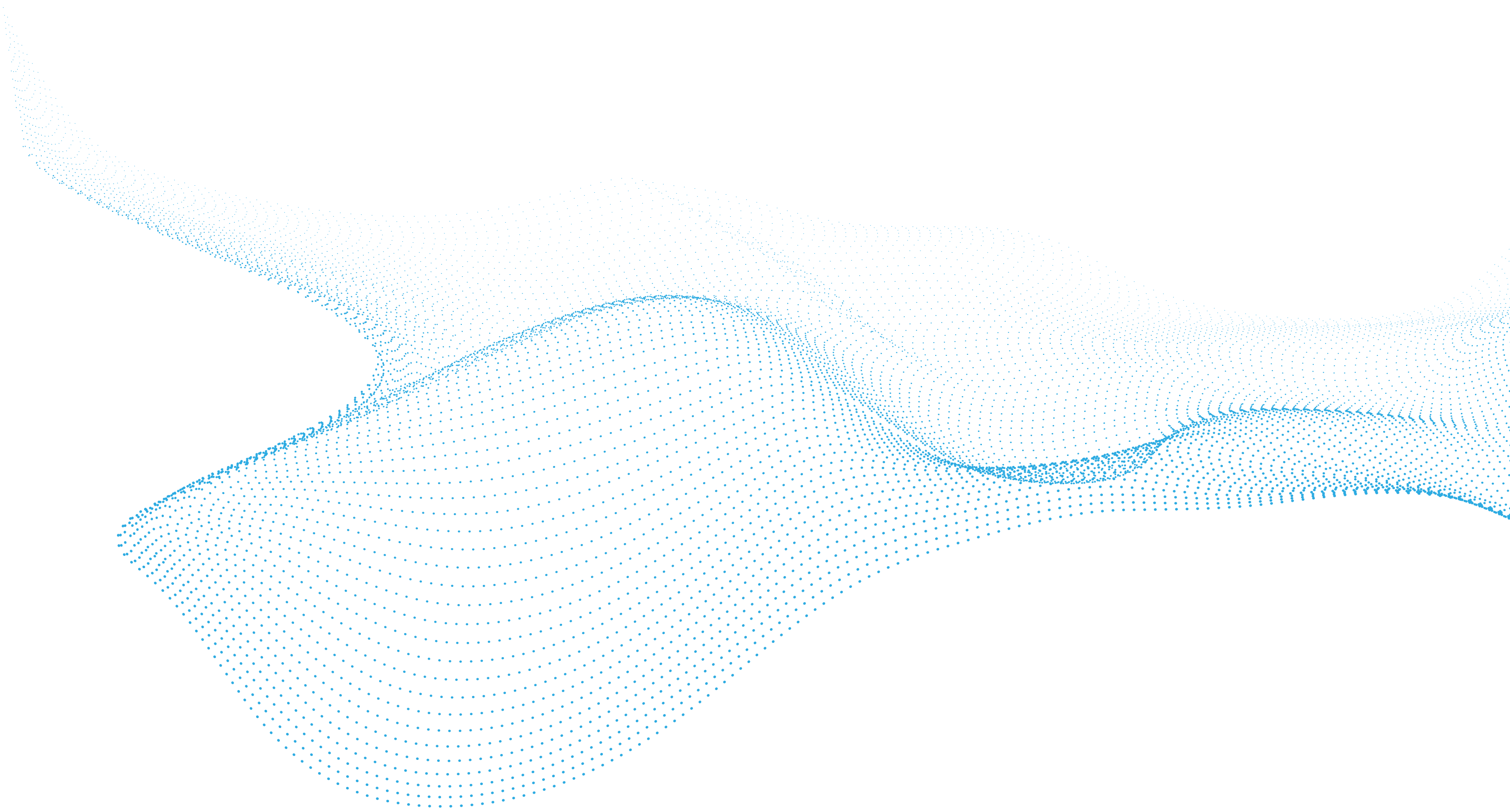
Key principles

- Acknowledge gender diversity and pronouns. Recognise that gender exists beyond the binary. Respect and include trans, non-binary, gender-diverse, and other gender identities.
- Foster safe and inclusive spaces. Use inclusive language, provide options for self-identification of gender and pronouns, and ensure research environments are free from discrimination.
- Enable meaningful participation. Involve gender-diverse individuals in research design, leadership and decision-making. Offer appropriate support to enable safe and equitable involvement.
- Respect privacy and autonomy. Keep lived experience experts' gender identity confidential. Ensure informed consent includes control over data use, representation and disclosure.
- Embed gender considerations throughout the research. Integrate gender analysis into all stages of research—from framing questions to interpreting and reporting findings. Avoid assumptions and reflect diverse lived experiences.

Applying a gender-responsive approach improves ethical standards, fosters inclusion, and contributes to more accurate and impactful research outcomes.[108]

✓ **Best Practice Point**

For gender-responsive research, acknowledge gender diversity, foster safe and inclusive spaces, enable meaningful participation, respect privacy and autonomy, embed gender considerations throughout, and respect pronouns.



5.5 People with Disability

People with disability and impairments include those with post-traumatic stress disorder, memory problems, hearing and vision impairments, cognitive impairments, and mobility problems. These people face many barriers to healthcare service access due to affordability, communication difficulties and non-inclusive built environment design, and often face discrimination. To accommodate people with disability or impairments who wish to be involved in PFE, researchers may consider the following strategies.

- Provide flexibility in meeting attendance, both face-to-face and virtually. If the meeting is held face-to-face, then researchers must arrange for it to be held in a location that is easily accessible for the lived experience expert (wheelchair access, accessible parking, accessible bathrooms) and enables engagement (e.g. hearing loops). In addition, transport assistance (such as taxi service) must be provided to lived experience experts who have mobility problems. Some lived experience experts have assistance animals that must be accommodated in meetings.
- If the meeting is held virtually, ask what support is required (e.g., a person who can assist the lived experience expert) and what platform is preferred. Telephone dial-in may be useful for lived experience experts who have trouble with computer access.
- If the lived experience expert has memory or cognitive impairments, check that their support person or carer can recount the points discussed at the meeting. Allow space in discussion for individuals with delayed reaction in comprehension or ability to contribute. Use Easy Read resources.[109]
- Ask lived experience experts if their inclusion in the project requires other accommodations (e.g., providing the agenda in advance, in a format that they prefer and is easily accessible and using people-first language). Lived experience experts with vision impairments could use a screen reader or other assistive technology to review the agenda in advance. In addition, it is best practice to provide alternate text for images, graphs and videos for people with vision impairments.
- Ensure that the items discussed at meetings are delivered in simple language; avoid jargon. Provide a list of definitions of abbreviations and specialised terms.

✓ **Best Practice Point**

When working with people with disabilities, enquire about what support is needed or how the engagement processes should be modified to enable participation. Set flexible meeting arrangements (timing, format such as online/in-person, provide accessible facilities and transport, cater for support persons and animals).

5.6 Bereaved People

Bereaved people have experienced intense personal loss, and their grief and strong emotions should be respected and considered sensitively. Bereaved people have a right to be involved in research and its design.

Grief may be triggered by places, conversations and topics related to the bereavement, so involvement in research design may present grief triggers for bereaved people. Bereaved people should be informed of what is involved so they can consider whether involvement is feasible and appropriate for them.

Researchers need to consider the emotional and psychological safety of bereaved people and make reasonable efforts to promote it, without gatekeeping their emotions or their right to choose to be involved.

Key issues to consider

- Working with bereaved people as research team members can raise grief-related challenges, including drop-out and varying commitment; plan for how such issues can be resolved together, and develop a sensible and respectful strategy for maintaining support.
- Consider establishing a relationship with relevant local bodies, such as a consumer liaison team, complaints management team, or any other external entity with relevant experience that can be consulted for advice if/when issues arise.
- Consider enlisting the assistance of a psychologist with matters of psychological safety for bereaved people and research team members.

In-depth detail about key considerations for working with bereaved people is provided in Appendix D.2.

✓ Best Practice Point

When working with bereaved people, plan for how issues due to the grief experience can be resolved together. Create a sensible and respectful strategy that draws on all available psychological and other resources to support bereaved people’s engagement. Expect that some bereaved people will provide shorter-term commitment than others, and consider planning a sensible and respectful strategy for maintaining support over time.

5.7 Children and Young People

For the purposes of this document, the broad term ‘children and young people’ is used to refer to anyone aged 18 years or younger. More specifically, the term ‘child’ or ‘children’ are used to refer to people aged 0–12 years, with ‘young people’ used to refer to those aged 13–18 years. However, it is also important to recognise that children and young people’s chronological ages do not always correlate to their developmental age, so you should tailor your approach accordingly.

What can children and young people be engaged in?

Just like adults, children and young people have a right to have a voice in things that affect them, including research. Children and young people can be involved across the spectrum of research, including in research planning, design, conduct, and dissemination, and should be involved in the process as early as possible. However, involving children and young people in research requires different considerations and approaches than involving adults does, because children and young people span a range of age and developmental abilities, and have different reading, writing, physical and cognitive abilities. Typically, they are only able to participate at specific times, such as weekends or after school hours, and their involvement often relies on support from an adult. Children and young people frequently experience disempowerment when in settings involving adults, making meaningful participation challenging for them.

How can children and young people be engaged?

Children and young people can be involved in research in a range of ways.[110-113] In general, children and young people should be asked how they want to be engaged, so they can choose an option that feels safe and comfortable for them and suits their individual needs, time and interests. Some children and young people may want to be engaged through the life of the project, while others may prefer a one-off discussion.

Some options for involving children and young people in research include:

- individual meetings with a member of the research team
- as members of a one-off discussion group or meeting
- as members of an ongoing children and young persons’ advisory group or steering committee
- as co-researchers, alongside the adult research team
- as members of an advisory group that also includes adults (think carefully about how to engage and support children in these settings to balance power dynamics and enable age-appropriate discussions)

Whatever the method of engagement, adopt a child-centred, rights-based approach to working with and involving children and young people in research design. This will help to prioritise children and young people’s wellbeing, agency, voice and rights throughout their engagement. On a practical level, this might mean offering:

- flexible approaches to participation, including meeting times and places that suit children and young people’s needs
- clear discussion and agreement of roles and expectations
- age and developmentally appropriate information, discussions and activities
- appropriate support and training for children and young people, from both researchers and relevant trusted adults
- accessible options for participation of all children and young people, regardless of age, physical or cognitive abilities, reading and communication skills, technological literacy or availability, or other factors. Use Easy Read resources[109]
- engaging and fun activities for children and young people, whilst offering meaningful and authentic ways to share their views

Preparing to work with children and young people

Before you start designing research with children and young people, consider the following points.[110-113]

- **The purpose** of engaging children and young people in your research design and development. This might include considering:
    - the aim of your research
    - what their engagement will involve
    - their role and level of engagement (e.g., inform, collaborate, lead)
    - the impacts children and young people could have on your research and how you will evaluate them.
- Your **level of experience and training needs.** Explore options for mentorship, online or in-person training on co-design, lived experience expert and community engagement and involvement, or working with children in research to ensure you have the skills and knowledge to safely and effectively work with children and young people.
- Requirements for **child safety, use of photos and images, and consent.** Depending on where you work and live, you may need a national or state/territory-based police check and working with children permit, so make sure these are current and valid before you get started. It's also a good idea to consider how you will manage other aspects of child safety, such as:
    - whether and how will you explore and document agreement for children and young people to take part. This will be dependent on the nature of engagement, and may include documenting parental agreement or consent for their child's participation
    - how you will securely store personal details relating to participation
    - whether you have permission to take photos and videos of the materials developed or the children and young people who take part
    - how children and young people would like to be acknowledged for their contribution.
- The most appropriate **time** for your engagement activities. Children and young people usually have family, educational and social commitments. Being flexible about engagement activities is important, including organising activities after school hours, on weekends, or in school holidays. Consulting children and young people about the best times for them is always a good idea.
- The **space or place** that you use for activities involving children and young people. Select a space that accommodates their unique needs. Include space for breaks that allow children and young people to move freely and engage in age-appropriate activities during breaks (e.g., unstructured play for younger children).
    - For younger children, this might include offering child-sized chairs and tables, child-accessible bathrooms, space to play and move, and is safe (e.g., not adjacent to a main road, with fenced gardens or outdoor areas, sufficient shade, no open bodies of water such as pools or lakes).
    - For older children and young people, this may include internet access, a space to spend break times (e.g., an alternative meeting space), and chargers for personal electronic devices.
- Try to avoid venues that have an association with the child or their family member's hospitalisation. Ensure the venue has adequate, accessible and safe parking, and a space for parents to wait.

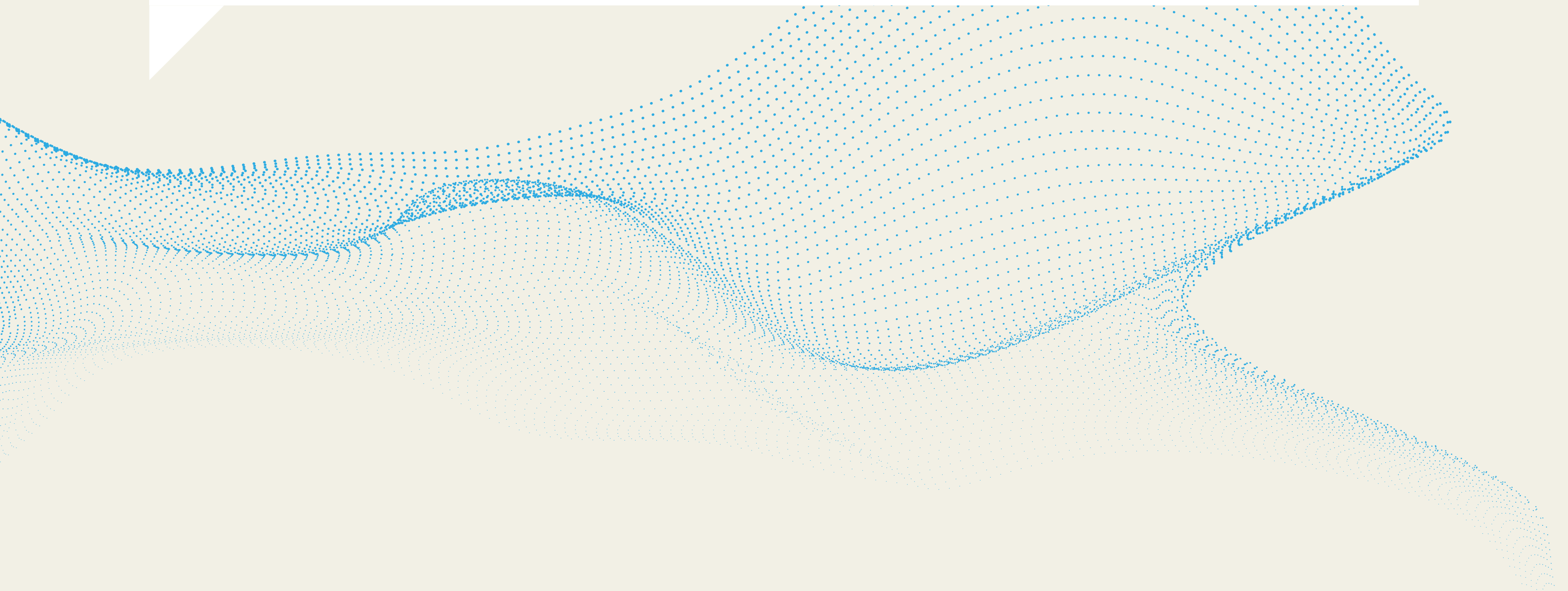
Further details about practical considerations and resources are provided in Appendix D.3.

✓ Best Practice Points

When engaging children and young people, use flexible participation methods and convenient meeting times and locations. Define roles and expectations clearly. Provide information, discussions and activities appropriate to participants' age and development. Offer support and training from researchers and trusted adults. Ensure all participation is accessible, regardless of age, abilities, literacy, and technology access. Include engaging activities that allow children and young people meaningful opportunities to share their views. Consider practical support for carers too (e.g., waiting area, refreshments, internet access).

Researchers must uphold child protection requirements when engaging with children.

> I was incredibly fortunate to be part of a clinical research trial bringing the extracorporeal membrane oxygenation heart-lung equipment to out-of-hospital cardiac arrests; a trial of a novel medical procedure and advanced technology that saved my life. I was therefore so pleased to be able to contribute to the development of guidelines designed to be a resource for researchers on approaches to successfully engaging with patients and families for future clinical research in intensive care.
>
> I hope that these guidelines further support the wellbeing of patients and their families during their very physically and emotionally challenging period in ICU and beyond, and provide useful guidance and resources to the medical researchers who are improving and saving the lives of those who are critically ill.
>
> Former ICU patient and lived experience representative



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Appendices

Appendix A: Appendix to Section 2 – Practical Considerations When Building and Sustaining Effective Partnerships

Appendix A.1: Helpful Resources When Beginning Patient and Family Engagement

The following are helpful resources when building partnerships with lived experience experts in critical care settings:

1. Consumer Engagement Organisations

   The following consumer engagement organisations can assist with identifying people with lived experience who may wish to partner in health research engagement activities. They also offer training sessions and courses that can be tailored to the needs of groups and services.

   - Health Care Consumers' Association (https://www.hcca.org.au/)
   - Consumers Health Forum of Australia (https://www.chf.org.au/)
   - Health Consumers NSW (https://hcnsw.org.au/)
   - Consumer health forum Aotearoa (https://www.hqsc.govt.nz/consumer-hub/consumer-health-forum-aotearoa/)

2. Research Education and Training Program RETProgram Education Module: Consumer and Community Involvement in Health Research

   This free online interactive course explains community participation and engagement in research. Access here: https://www.retprogram.org/training/consumer-and-community-involvement-in-health-research

3. Western Australian Health Translation Network Consumer and Community Involvement Program training options.

   Free workshops to supports consumers and community members to develop understanding, skills and confidence about becoming actively involved in research. Access here: https://cciprogram.org/community-involvement/#training

4. Monash Partners Consumer and Community Involvement online modules

   Free online training modules primarily designed to support the needs of researchers and healthcare professionals. Access here: https://monashpartners.org.au/education-training-and-events/cci/

5. Australian Institute of Aboriginal and Torres Strait Islander Studies (AITSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research

   Access here: https://aiatsis.gov.au/sites/default/files/2020-10/aiatsis-code-ethics.pdf

6. Te Ara Tika Guidelines for Māori Research Ethics

   Access here: https://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics-0

7. Sharing power in global health research: an ethical toolkit for designing priority-setting processes that meaningfully include communities. An ethical toolkit and effective project planning aid to use before performing research priority-setting. It aims to create more inclusive processes that are less likely to reinforce hierarchies of privilege and subordination. Access here: https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-021-01453-y

Appendix A.2: Legislative Documents That Underpin Consumer Engagement in Aotearoa New Zealand

Consumer engagement in a health care setting is underpinned by four legislative documents Te Tiriti o Waitangi (the Treaty of Waitangi), the Code of Health and Disability Services Consumers' Rights (the Code), the New Zealand Public Health and Disability Act 2000 and the Pae Ora (Healthy Futures) Act 2022. Further details about these legislative documents are provided here.

Te Tiriti o Waitangi

Te Tiriti o Waitangi is considered a foundational document for Aotearoa NZ and outlines an agreement between the tangata whenua and the Crown. The principles of Te Tiriti o Waitangi guide relationships and interactions between Māori, the Crown, and all individuals/organisations that live in Aotearoa NZ. Recognition and respect for the principles of Te Tiriti o Waitangi is included in the New Zealand Public Health and Disability Act 2000.

The Waitangi Tribunal's Health Service and Outcomes Inquiry (Wai 2575) defines the principles as:

- Self-Determination | Tino rangatiratanga: Māori self-determination and mana motuhake
- Partnership | Pātuitanga: forming strong, respectful and enduring relationships at all levels of health care delivery from design to provision of services
- Equity | Mana taurite: committing to treating lived experience experts equitably, eliminating funding inequities and barriers to accessing care which may contribute to equitable health outcomes for Māori
- Active protection | Whakamarumarutia: health professionals are trained in and practice in a culturally safe manner
- Options | Kōwhiringa: ensuring that health services are provided in a culturally appropriate way that recognises and supports the expression of te ao Māori (Māori worldview and traditions)

Code of Health and Disability Services Consumers' Rights

Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 (the Code) defines the rights of health lived experience experts and the obligations of health care and disability services providers. Every consumer has the rights in the Code and every provider is subject to the obligations in the Code.

Right 1 states that lived experience experts have the right to be provided with services that consider the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori.

Code of expectations for health entities' engagement with lived experience experts and whānau

In addition to legislation, Aotearoa NZ has a code of expectations (the Code of expectations for health entities' engagement with lived experience experts and whānau) for how health entities must work with lived experience experts in the planning, design, delivery, and evaluation of health services. This code is required by the Pae Ora (Healthy Futures) Act 2022 and retained in the amended Pae Ora (Disestablishment of Māori Health Authority) Amendment Act 2024. All health care entities must adhere to the code. The engagement expectations include valuing and recognising the importance of te ao Māori (Māori worldview), providing opportunities for Māori to exercise decision-making authority, promoting equity particularly with Māori, Pacific peoples, and disabled people.

The code of expectations also outlines how health entities must apply the expectations including co-designing with lived experience experts, using lived experience of lived experience experts to inform improvement in health services particularly to reduce health inequities, and resourcing lived experience experts to contribute and engage meaning fully.

Vision Mātauranga

Vision Mātauranga is a policy framework that describes a strategic direction for research of relevance to Māori. While this document is intended for research funded through the NZ Government's Vote Science & Technology fund, it provides a good outline of what research is important for Māori communities and thus what ANZICS should consider when designing clinical trials/studies to advance Māori health equity. One key purpose is 'Hauora/Oranga: Improving Health and Social Wellbeing.' We recommend researchers to look at the document in further detail here: Vision Mātauranga.

Appendix B: Appendix to Section 3 – Guiding Principles for Patient and Family Engagement in Critical Care Research and Registries

Appendix B.1: Checklist for PFE in Critical Care Research

The below checklist outlines opportunities for engagement with lived experience experts during the research study lifecycle. It is recommended the research team identify which of these opportunities would be relevant for their study. Note that this is not an exhaustive list, nor is it assumed that all items are relevant for each study; only those engagement opportunities relevant to the study design, study resourcing, expertise of researcher, and of interest to the lived experience experts, should be considered.

To guide researchers new to PFE in critical care research, 2–3 opportunities (indicated with a #) within each section have been identified as potential starting points for involving lived experience experts in research.

✔	Engagement Opportunity
✔	**Design**
○	#Have lived experience experts been involved in co-designing the research questions and objectives to ensure they reflect patient and family priorities?
○	Have lived experience experts contributed to defining eligibility criteria to ensure inclusivity and real-world relevance?
○	#Have patient-centred outcomes (e.g. quality of life, functional status) been selected or developed with input from lived experience experts?
○	#Have consent materials and processes been reviewed by lived experience experts for clarity, cultural appropriateness, emotional sensitivity, and timing, approach, and from whom the consent is sought?
○	Have recruitment strategies been informed by lived experience experts to ensure they are accessible, inclusive, and participant-friendly?
○	Have lived experience experts provided feedback on data collection methods to ensure they are acceptable and feasible for participants?
○	Have lived experience experts helped determine how and when participants will receive information about study procedures and results?
○	Have mechanisms been established for lived experience experts to provide ongoing input and influence key design decisions?
○	Have you documented how lived experience expert contributions have shaped the study design and acknowledged their input appropriately?
✔	**Conduct**
○	#Are lived experience experts represented on governance structures (e.g. Steering Committees, Study Management Teams), with appropriate psychological safety and support mechanisms and remuneration?
○	Have you included more than one lived experience expert in governance groups to avoid tokenism and support shared representation?
○	Have lived experience experts been supported to lead or co-lead Consumer Advisory Groups, including setting agendas and reporting to governance bodies?
○	Have lived experience experts been invited to provide real-time feedback on participant recruitment, retention, and consent processes?
○	#Have lived experience experts helped shape flexible and responsive follow-up strategies to support participant retention?
○	Have opportunities been created for consumer-led sub-studies on priority topics?
○	#Have lived experience experts contributed to developing or reviewing participant-facing communications for amendments and/or study updates?

✓	**Interpret**
○	Have lived experience experts been invited to participate in interpreting qualitative and/or quantitative data?
○	Is the level of lived experience expert involvement (consultative, collaborative, co-analyst) clearly defined and documented?
○	#Have tools, training, or support been provided to lived experience experts to enable meaningful participation in data interpretation?
○	Have diverse perspectives been included, especially from under-represented or vulnerable groups?
○	Have lived experience experts helped identify ethical, cultural, or contextual factors influencing interpretation?
○	Have lived experience experts contributed to identifying and addressing potential stigmas or biases in data interpretation?
○	#Have unexpected or unusual findings been explored with lived experience expert input?
○	Have differing interpretations between lived experience experts and researchers been acknowledged and documented?
○	Have health and functional needs of lived experience experts been considered in planning their involvement?
○	#Has the impact of lived experience expert involvement in interpretation been reflected in the final outputs (e.g. publications, reports)?
✓	**Dissemination**
○	Have lived experience experts been invited to co-develop or review dissemination materials (e.g. summaries, infographics, presentations)?
○	Have lived experience experts been offered opportunities to co-author academic publications or review drafts for clarity and relevance?
○	Have lived experience experts been supported to co-present findings at conferences, webinars, or workshops?
○	#Have dissemination strategies included community-facing formats (e.g. forums, advocacy groups, social media)?
○	Have lived experience experts been involved in shaping messaging to ensure it is meaningful and accessible to patients and families?
○	Have training and mentorship been offered to lived experience experts for public speaking, writing, or media engagement?
○	Have roles and expectations for dissemination activities been clearly defined with lived experience experts?
○	Have logistical supports (e.g. travel, preparation time, honoraria) been provided to enable lived experience expert participation?
○	#Has the GRIPP2 framework been used to report lived experience expert involvement in dissemination activities?
○	#Have lived experience expert contributions been acknowledged through authorship, credits, or public recognition?

✓	**Paediatric-specific Considerations**
○	#Has a broad range of lived experience experts relevant to the paediatric-focussed question (e.g. children, parents, carers, siblings, extended family) been identified and included?
○	#Has appropriate consent and assent been obtained for involving children or young people?
○	Are communication methods age-appropriate and inclusive of creative or alternative engagement strategies?
○	Have ethical safeguards been put in place, including trained professionals and post-engagement support?
○	Have scheduling and participation methods been adapted to suit the needs and routines of children and families?
○	#Have contributions from children and families been acknowledged in meaningful and age-appropriate ways?

Appendix B.2: Checklist for PFE in Clinical Quality Registries

The below checklist outlines opportunities for PFE for clinical quality registries (CQR). It is recommended the CQR governance team identify which of these opportunities would be relevant for their registry. Note that this is not an exhaustive list, nor is it assumed that all items are relevant for each registry; only those engagement opportunities relevant to the registry content, resourcing, expertise of CQR governance team, and of interest to the lived experience experts, should be considered.

To guide CQR teams new to PFE, 2-3 opportunities (indicated with a #) within each section have been identified as potential starting points.

✓	Engagement Opportunity
✓	**Design**
○	#Have lived experience experts been involved in co-designing CRQ objectives to ensure they reflect patient and family priorities?
○	Have lived experience experts contributed to governance structures to ensure real-world relevance?
○	#Have patient-centred outcomes (e.g. quality of life, functional status) been selected or developed with input from lived experience experts?
○	#Have publicly facing materials, including opt-out processes, been reviewed by lived experience experts for clarity, cultural appropriateness, and emotional sensitivity?
○	Have lived experience experts provided feedback on publicly facing data collection methods to ensure they are acceptable and feasible for participants?
○	Have lived experience experts contributed to selecting indicators that are meaningful and actionable from a patient perspective?
○	Have mechanisms been established for lived experience experts to provide ongoing input and influence key design decisions?
○	Do governance policies and documents include how and when lived experience experts contributions are sought, and that lived experience experts are acknowledged appropriately?
✓	**Conduct**
○	#Are lived experience experts represented on governance structures (e.g. Steering Committees, Study Management Teams), with appropriate psychological safety and support mechanisms and remuneration?
○	Have you included more than one lived experience expert in governance groups to avoid tokenism and support shared representation?
○	Have lived experience experts been supported to lead or co-lead Consumer Advisory Groups, including setting agendas and reporting to governance bodies?
○	Have opportunities been created for consumer-led sub-studies on priority topics?
	#Have lived experience experts contributed to developing or reviewing participant- or public-facing communications?

✓	**Interpret**
○	Have lived experience experts been invited to participate in interpreting qualitative and/or quantitative data?
○	Is the level of involvement (consultative, collaborative, co-analyst) clearly defined and documented?
○	#Have tools, training, or support been provided to enable meaningful participation in data interpretation?
○	Have diverse perspectives been included, especially from under-represented or vulnerable groups?
○	Have lived experience experts helped identify ethical, cultural, or contextual factors influencing interpretation?
○	Have lived experience experts contributed to identifying and addressing potential stigmas or biases in data interpretation?
○	#Have unexpected or unusual findings been explored with lived experience expert input?
○	Have differing interpretations between lived experience experts and researchers been acknowledged and documented?
○	Have health and functional needs of lived experience experts been considered in planning their involvement?
○	#Has the impact of lived experience expert involvement been reflected in reporting?
✓	**Dissemination**
○	Have lived experience experts been invited to co-develop or review dissemination materials (e.g. summaries, infographics, presentations)?
○	Have lived experience experts been supported to co-present findings at conferences, webinars, or workshops?
○	#Have dissemination strategies included community-facing formats (e.g. forums, advocacy groups, social media)?
○	Have lived experience experts been involved in shaping public-facing messaging to ensure it is meaningful and accessible to patients and families?
○	Have training and mentorship been offered to lived experience experts for public speaking, writing, or media engagement?
○	Have roles and expectations for dissemination activities been clearly defined with lived experience experts?
○	Have logistical supports (e.g. travel, preparation time, honoraria) been provided to enable lived experience expert participation?
○	Has the GRIPP2 framework been considered to report lived experience expert involvement in dissemination activities?
○	#Have lived experience expert contributions been acknowledged through authorship, credits, or public recognition?
✓	**Paediatric-specific Considerations**
○	#Has a broad range of lived experience experts relevant to the paediatric-focussed question (e.g. children, parents, carers, siblings, extended family) been identified and included?
○	#Has appropriate consent and assent been obtained for involving children or young people?
○	Are communication methods age-appropriate and inclusive of creative or alternative engagement strategies?
○	Have ethical safeguards been put in place, including trained professionals and post-engagement support?
○	Have scheduling and participation methods been adapted to suit the needs and routines of children and families?
○	#Have contributions from children and families been acknowledged in meaningful and age-appropriate ways?

Appendix C: Appendix to Section 4 – Measuring the Impact of Patient and Family Engagement

The table below outlines the major tools available to assess the impact of patient and family engagement in research.

Patient and Family Engagement Impact evaluation tools

Tool	Country	Type of tool	Respondents	Purpose/areas of impact	Reference, URL, More information
Patient engagement evaluation tool (PEET)	Canada	Questionnaire PEET-6 item PEET-12 item Validated	Patients and members of the public on guideline development teams	To inform guideline developers about the quality of patient and public involvement activities. Theory informed measure of the extent to which criteria are met across domains including trust fairness, competency, legitimacy and accountability from a participant's perspective.	https://www.jclinepi.com/article/S0895-4356(21)00392-9/fulltext Moore A et al J Clin Epidemiol . 2022 Mar:143:61-72. doi: 10.1016/j.jclinepi.2021.11.034.
Patient-Led Research Scorecards	US, Canada Collaboration between The Council of Medical Specialty Societies (USA based) and Patient-Led Research Collaborative	Patient-Led Scorecards	• Patients/ Patient organisation • Researchers/ Research Institute • Funders	Patient-led scorecards which serve to evaluate how effective a patient group and research partner collaboration will be at conducting truly patient-led research. Four areas of importance to patient led collaborative research • Integration into Research Process • Patient Burden • Research Organization Readiness • Patient-Partner governance Collaboration Scoring [-2,-1,0,+1,+2]	https://patientresearchcovid19.com/wp-content/uploads/2024/10/Patient-Led-Research-Scorecards-CMSS-NHS-patient-centered-partnership-Summit.pdf https://patientresearchcovid19.com/storage/2023/02/Patient-Led-Research-Scorecards.pdf

Tool	Country	Type of tool	Respondents	Purpose/areas of impact	Reference, URL, More information
Patients Canada	Canada	Patients as Partners in Research 3 surveys Initial - in the early stages of the partnership Mid - mid-way through the research project End - after the research is completed	Patients/ Caregivers Researchers	Surveys assess the actual experience of researchers when they partner with patients and caregivers on a project where the patients and/or caregivers are members of the research team. Surveys of patients/ caregivers have the same goal: to understand their experience when associating with researchers. Surveys are multiitem • Initial: 65-77 items • Mid: 38-41 items • End: 39-43 items	Online: https://ossu.ca/for-patients/resources Patient/Caregiver's survey: https://ossu.ca/wp-content/uploads/EvaluationSurveysPatient_2016.pdf Researcher's survey: https://ossu.ca/wp-content/uploads/Evaluation-SurveysResearcher_2016.pdf
Health Lived experience experts Centre (Previously Health Issues Centre)	Australia	Evaluation of consumer engagement for organisations	Staff Researchers	Evaluation of consumer engagement in research teams. Includes process and outcome of consumer engagement sample questions	https://nswregionalhealthpartners.org.au/wp-content/uploads/2023/04/Health-Issue-Centre-Evaluation-of-consumer-engagement-Template.pdf
Sydney Health Partners	Australia	Scoring matrix	Grant reviewers which may include researchers, lived experience experts and carers	Describing and Assessing Consumer Involvement in Health Research in Funding Applications	https://sydneyhealthpartners.org.au/news/new-consumer-involvement-guide-helps-both-researchers-and-grant-reviewers/
NHMRC	Australia	Checklist	Researchers	Measuring Effectiveness of Consumer and Community Involvement in Research	NHMRC (National Health and Medical Research Council)

Tool	Country	Type of tool	Respondents	Purpose/areas of impact	Reference, URL, More information
NHMRC	Australia	Reporting checklist	Researchers	Self-assessment of lived experience experts and community involvement in the research journey	NHMRC (National Health and Medical Research Council)
Australian Clinical Trials Alliance (ACTA) Evaluating Impact	Australia	3 tools: • Consumer involvement evaluation form • Consumer involvement evaluation form for a one-off event • Consumer involvement project evaluation form	• Lived experience experts • Researchers • Group of consumer representatives and researchers	This tool assesses the impact of consumer engagement across seven key domains: patient-centeredness, meaningfulness, ethical design, feasibility, understandability, generalisability, and legitimacy. Helps to identify specific examples of impact.	https://involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/evaluating/evaluating-involvement/ ACTA Consumer Involvement and Engagement Toolkit: This toolkit offers practical advice for researchers, including guidance on planning, delivering, evaluating, and reporting consumer involvement activities. It uses an interactive map to guide researchers through different stages of engagement.
Quality and Impact of Patient and Public involvement (PPI)	UK	Questionnaire	Researcher and Consumer versions	Reporting on various aspects of Patient and Public Involvement experience and impact in a project. Require revision and modification for the Australian context.	Blackburn et al. (2018). The extent, quality and impact of patient and public involvement in primary care research: a mixed methods study. Research Involvement and Engagement, 4: 16. Note: Researcher and Consumer versions of the tool are provided in files at the bottom of webpage. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0100-8

Tool	Country	Type of tool	Respondents	Purpose/areas of impact	Reference, URL, More information
Public and Patient Engagement Evaluation Tool (PPEET)	Canada	Questionnaire	Consumer, Project (Researchers) at 3 stages of research, and Organisational versions • Organization questionnaire • Participant questionnaire • Project Questionnaire	Examines range of processes and impacts of Consumer and Community Involvement • Versions for short term consumer engagement and longer-term involvement • Can be tailored for different respondents and project types/stages	McMaster University. (2018). Public and Patient Engagement Evaluation Tool V2. https://ppe.mcmaster.ca/our-products/public-patient-engagement-evaluation-tool * Licensed, Tool available free upon request
Public involvement Impact Assessment Framework (PiiAF)	UK	Guide for research teams to undertake an interactive group process to review, understand and guide consumer involvement approach	Research teams, which could include consumer partners	To help researchers assess the impacts of involving members of the public in health and social care research Values, research approaches, practical issues and impacts • tailored to research project and context • Evaluation process could also be a capacity building for research team	Popay, J., M. Collins, and with the PiiAF Study Group. "The public involvement impact assessment framework guidance." Universities of Lancaster, Liverpool and Exeter (2014). https://www.bangor.ac.uk/health-sciences/documents/piiaf-guidance-jan14.pdf
National Health Service consumer involvement survey	UK	Questionnaire	Researchers	Indicators for monitoring and reporting on the quality of consumer engagement/involvement in a project. Would need some revision for the Australian context	Barber et al. (2007) Involving lived experience experts successfully in NHS research: a national survey. Health Expectations, 10(4): 380-391. https://pubmed.ncbi.nlm.nih.gov/17986074/

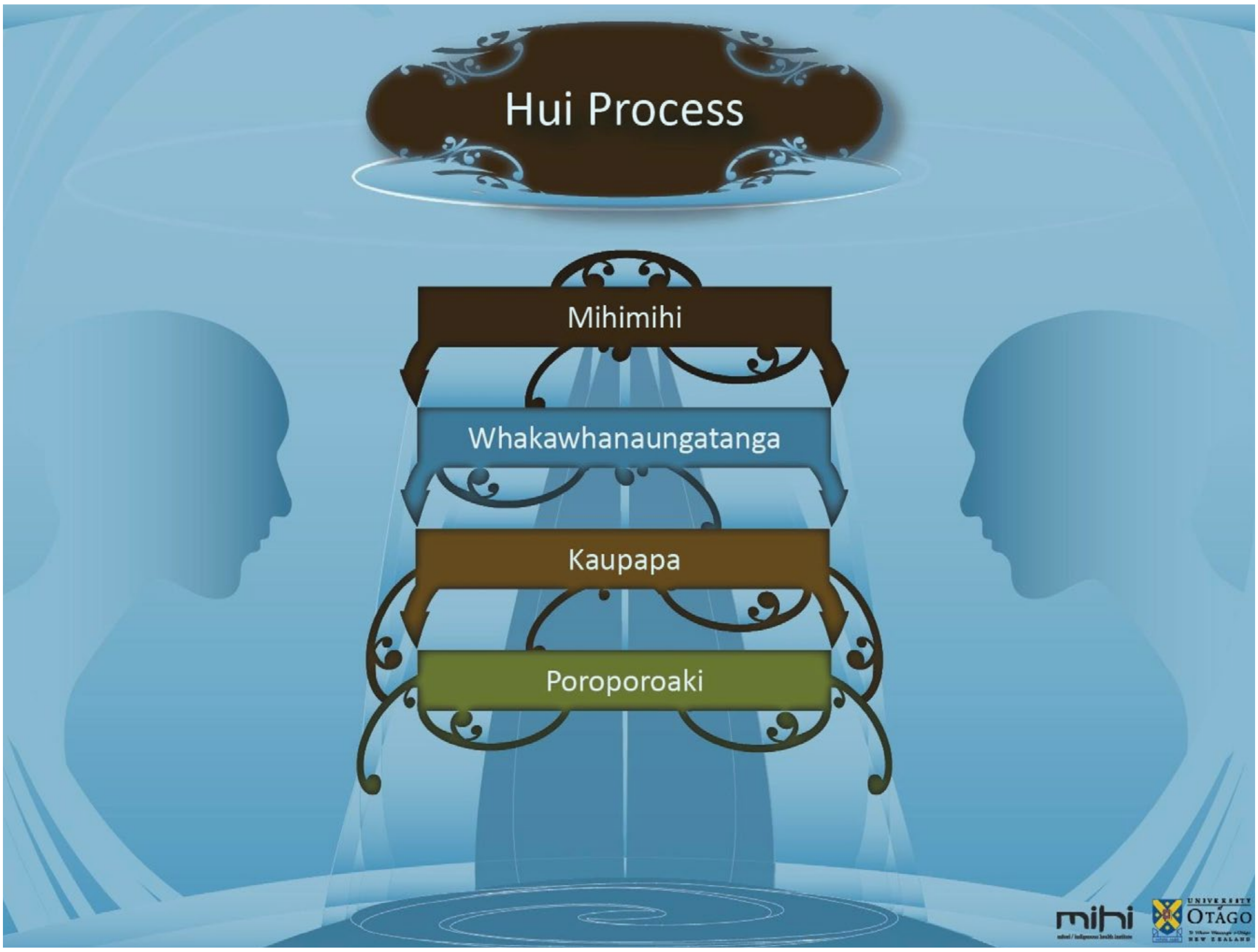
Tool	Country	Type of tool	Respondents	Purpose/areas of impact	Reference, URL, More information
Patient-Centred Outcomes Research Institute (PCORI)	USA	Questionnaire and interview	Researchers	Evaluates engagement with a range of research stakeholders including patients and the public. – Some questions relate to the impact of patient engagement	PCORnet Engagement Assessment Project: Findings and Recommendations, 2018. https://www.pcori.org/sites/default/files/4089-PCORnet-Engagement-Assessment-Project-Findings-and-Recommendations.pdf
Vale et al 2012	UK	Questionnaire	Researchers	Respondents identify types of impact using open-ended questions. Would need some revision for Australian context	Vale C, Thompson LC, Murphy C, Forcat S, Hanley B. (2012). Involvement of lived experience experts in studies run by the Medical Research Council Clinical Trials Unit: Results of a survey. Trials, 13: 9.
GRIPP2 reporting checklist	UK	List of items to report on – long and short version.	Research team which may include lived experience experts	Tool aims to standardise reporting of PPI in research – Reports nature and extent of consumer involvement in the projects aims, methods, results, conclusions and outcomes, and included reflections on processes and learning for the future	https://www.equator-network.org/reporting-guidelines/gripp2-reporting-checklists-tools-to-improve-reporting-of-patient-and-public-involvement-in-research/

Appendix D: Appendix To Section 5 – Applying the Principles of Engagement in Partnership With Diverse Groups

Appendix D.1: Recommended Frameworks to Help Guide Researchers and Clinicians in Their Interactions With Māori Patients and Whānau

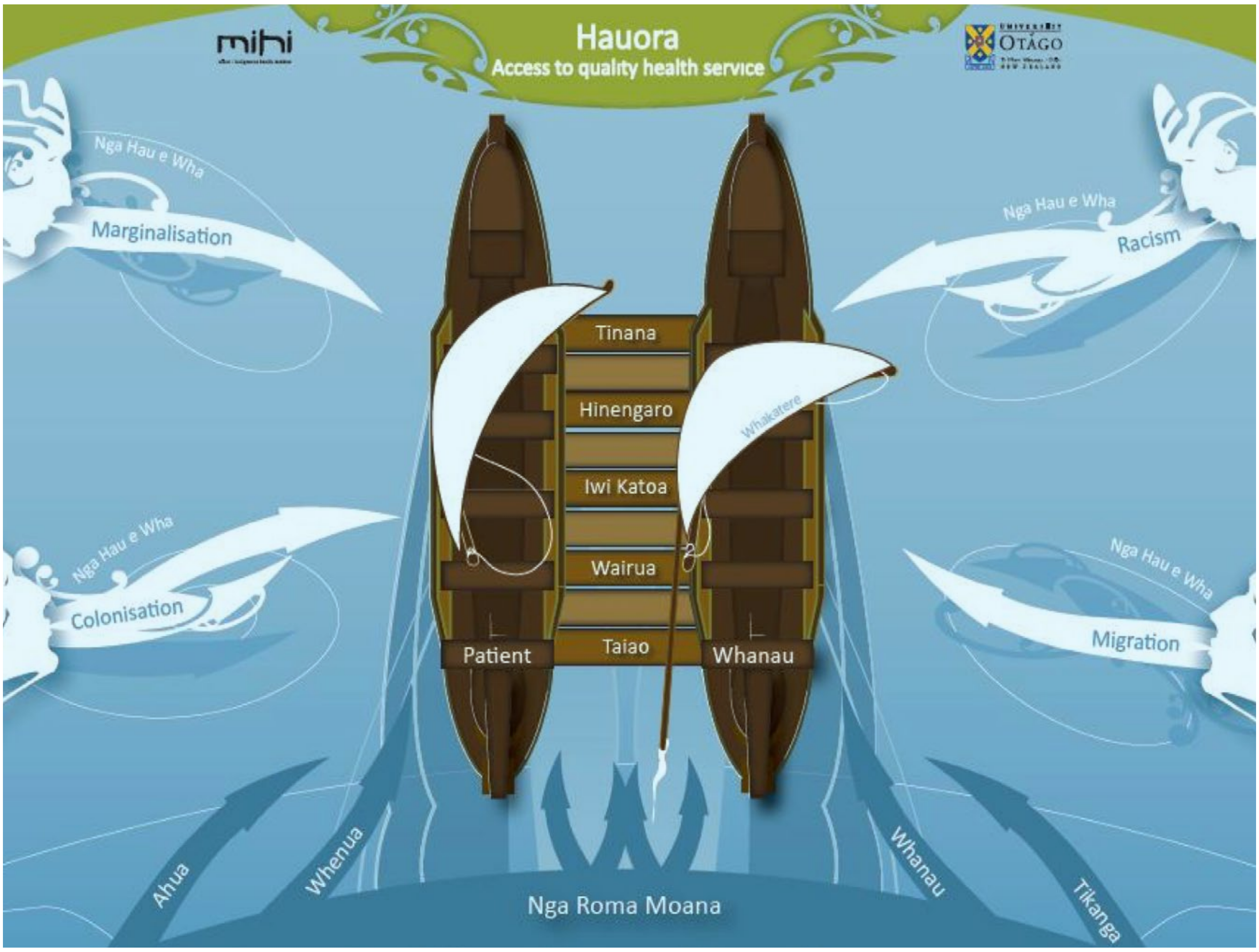
Three recommended frameworks to help guide researchers and clinicians in their interactions with Māori patients and whānau are The Hui Process, the Meihana model and Te Wheke.

Figure 1 - Hui Process



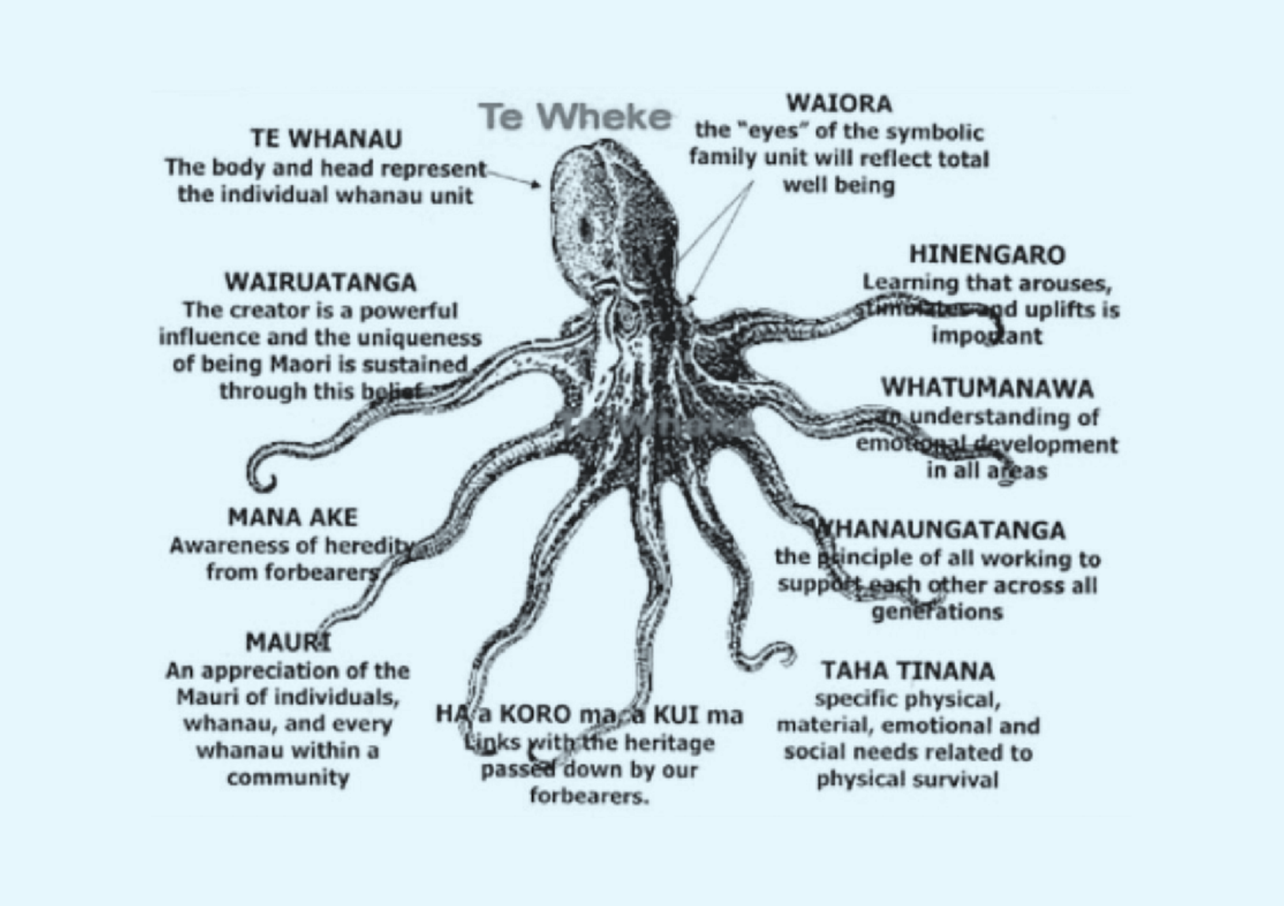
The Hui Process (Figure 1) is a model developed by Māori health researchers to guide culturally safe interactions with clinicians and their Māori patients, and can be used to help researchers engage with Māori lived experience experts (95). The model describes traditional principles of mihi (greeting), whanaungatanga (introducing, relationship building), kaupapa (topic discussion) and poroporoaki (concluding an encounter) (95). A detailed description of the model can be found here: The Hui Process (95).

Figure 2 - Meihana Model



The Meihana Model (Figure 2) is a Māori health framework that is based on the frame of a waka Hourua (double hulled boat) to show the different elements that influence a patient’s health journey (114). The model describes physical, mental, spiritual, environmental, and social domains of wellbeing for both the patient and their whānau (114). These domains are guided by four ocean currents (family, tikanga (protocols), ahua (Te Ao Māori) and whenua (the land)) (114). Lastly, the model acknowledges the winds of colonisation, marginalisation, racism, and migration which have influenced Māori health and wellbeing (114). Researchers can read the detailed version of the model here: The Meihana Model.

Figure 3 - Te Wheke



Rose Pere's Te Wheke model of health is another framework that highlights the holistic domains of Māori health (96). This model highlights the importance of spiritual and cultural wellbeing for Māori communities, with the involvement of whānau (family) at the foundation. Te Wheke provides health practitioners with a deeper perspective of Māori hauora (wellbeing) than Te Whare Tapa Whā.

Appendix D.2: Working With Bereaved People to Design Research

This section details key considerations when working with bereaved people to design research.

Inviting engagement in research

- Inviting bereaved people to contribute in research as lived experience experts requires sensitivity, and careful consideration should be given to the methods and materials used.
- Consider recruiting through bereavement-sensitive methods such as:
    - word-of-mouth via bereavement support groups.
    - direct contact with bereaved people who have expressed interest in involvement with hospital or research-related activities – bereaved people may feel a strong connection to the place where their loved one died or was cared for prior to death and may personally initiate ongoing contact. Following this self-expressed lead can provide a respectful opportunity to recruit bereaved people to be involved in research design.
- Snowball recruitment via experienced lived experience experts who have connections with bereaved people or relevant community groups.
- Consider using bespoke materials and processes that are sensitive to bereavement such as:
    - Providing early opt-out opportunities with initial contact so that bereaved people who do not feel comfortable discussing research involvement can message NO and know that they will not be contacted again, while those who feel emotionally capable can message YES and indicate they are open to contact.
- Designing social media or physical recruitment posters that use sensitive language and images chosen carefully with bereavement in mind, to use in carefully chosen settings, avoiding general public posting.
- Producing information materials about involvement that cover issues specific to bereaved people such as an overview of the psychological safety measures that will be in place, the level of commitment required and the opportunities to cease involvement if required for personal emotional and psychological reasons, as well links to relevant support services.
- Ensure recruitment materials clearly define the scope of "bereaved people" and the types of loss being considered for the research involvement (e.g., loss of a child, family member). Explicitly state whether this includes losses such as early pregnancy loss (miscarriage) or stillbirth to avoid ambiguity and ensure individuals who have experienced these specific types of bereavement are aware of their potential eligibility and the research focus.
- An experienced consumer representative can play an important role in advising on and refining recruitment strategies to ensure they are appropriate, sensitive, and effective in reaching and engaging bereaved individuals.

Training

- Seek opportunities for relevant training related to working with bereaved people. This might include:
    - communication skills training
    - therapeutic conversation techniques
    - training or education related to grief and bereavement theories and approaches
    - Trauma Informed Care
    - Mental Health First Aid training
- Consider additional training needs specific to the population you are hoping to work with. For example, you might need to undertake some training related to working with bereaved people from First Nations communities, to ensure your approach is culturally safe and appropriate.
- If possible, consider receiving mentorship or support from a researcher or clinician who is experienced in working with bereaved people.
- Provide specific training for bereaved lived experience experts to help them understand the research process and their role within it, which can assist in moving beyond individual experiences to contribute to broader research design considerations.

Communication

- Explore individual preferences for how to refer to death and dying (e.g. loss, passed away, died, moved on, etc.).
- Explore cultural or religious considerations around using the name of the deceased person, the cause of death, or any other relevant considerations.
- Carefully consider the timing of involvement. Some evidence suggests that 6-24 months post bereavement is the ideal timeframe to take part in research, but this is individual to each person, and broader timeframes may be appropriate in some situations.
- Avoid contact or meetings on key dates, including:
    - Anniversaries (of death, of funerals, of admission to hospital)
    - Birthdays
    - Special occasions like religious holidays, Mothers/Father's Day, etc
- Where possible, clearly indicate the purpose of the letter or email as quickly as possible (e.g. on the envelope or in the Subject line), so people can open it when they feel ready.
- Recognise that bereaved people are often connected to valuable networks, support groups, and communities. Engaging with these existing structures can provide effective avenues for disseminating research findings to those who may benefit most from the information.

Meetings

- Where possible, avoid having meetings in places that may be associated with trauma or death, such as hospitals.
- Consider appointing a bereaved person as co-chair to elevate the voice of bereaved members and ensure the meetings are conducted in a way that reflects their priorities.
- Be flexible in how people can take part and offer options for both in person and online participation.
- During meetings, ensure there are opportunities to take breaks, stop taking part, or remove oneself to another location as needed.
- Ensure you have resources and support services available, such as information on grief and local grief support services, debriefing options, or availability of counselling or psychological support.
- Develop a psychological safety plan for all members of the team and ensure this is always available.
- Check in with everyone regularly to assess wellbeing and mental health, as well as support needs or concerns.
- Actively involve bereaved people in the development of the Terms of Reference for their involvement in the research design, ensuring the scope and expectations of their contribution are mutually agreed upon and sensitive to their experiences.
- Given the potentially heavy and emotionally challenging themes, it is advisable to request that bereaved people arrange childcare and avoid bringing children to meetings to ensure a focused and supportive environment for all participants.
- Consider incorporating brief, optional rituals or acknowledgements of loss at the beginning of meetings, such as a moment of silence or an invitation (not obligation) to briefly mention their loved one if they feel comfortable. These should be discussed and agreed upon with the bereaved lived experience experts.

Remuneration and Support

- Recognise the value of bereaved peoples' contributions and ensure equitable access to participation by providing remuneration that covers their time commitment, travel expenses, and any childcare requirements. This demonstrates respect for their involvement and helps remove potential barriers to participation.
- Consider providing access to training, debriefing and emotional support resources.

Retention of Group Members

- Retaining positive engagement over time is an important aspect of working with people with lived experience and requires an effective partnership between researchers and bereaved people.
- Consider planning together at the commencement of the partnership to ensure that the expected commitment over time is clear, and that the goals of ongoing engagement are aligned between researchers and bereaved people.
- Consider inviting bereaved people to contribute their own goals and priorities for the partnership to ensure that ongoing commitment is meaningful to them.
- Potential opportunities for bidirectional engagement might include:
  - Sharing project progress and outputs with bereaved people to ensure they are valued partners in the project rather than one-way contributors.
  - Offering the opportunity for researchers to speak at bereavement community events that are important to the bereavement community.
  - Inviting bereaved people to present alongside researchers at scientific conferences.
  - Offering bereaved people co-authorship on research publications.
  - Considering shared social media and online engagement opportunities that highlight the research focus or project progress milestones alongside bereavement community priorities and current events that are meaningful to bereaved people.
  - Inviting bereaved people to design and lead a community dissemination plan for research results drawing on their own community connections, such as bereavement forums and sharing of personal stories and testimonials.
- Acknowledge the potential impact of ongoing research engagement on the experience of grief for each bereaved person and consider ways to minimise emotional burden over time.
- Strategies to reduce emotional burden over time might include:
  - Tailoring levels of engagement to the life-cycle of the research project – scheduling meetings or engagement with bereaved people according to specified tasks, needs or priorities rather than regular engagement without a clear, purposeful focus.
  - Offering hybrid options for engagement such as inviting a larger group of people than required to contribute so that not all group members are required at every meeting and encouraging members to regularly take breaks from engagement according to their personal wellbeing needs and the demands of their own grief journey.

Further resources and reading

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Appendix D.3: Practical Considerations When Engaging With Children and Young People

This section details the practical aspects of engaging with children and young people from the planning phase, to conducting research and engagement, and how to conclude engagement activities.

Inviting children to take part

Inviting children and young people to take part in research co-design activities can be more challenging than inviting adults. It can be difficult to get in direct contact with children, and you may need to rely on adult gatekeepers, such as parents, carers, or group leaders to help pass along the opportunity. It's a good idea to begin your planning early and establish good relationships with relevant adults to support the children and young people who might be involved.

There are a number of avenues you might consider to help you connect with children and young people with ICU experience:

- Through connections with paediatric intensive care unit clinicians and families
- Through paediatric consumer representatives and groups within the local hospital
- Through condition specific family support organisations, especially those with support groups for children and young people, like Heart Kids Australia or Ronald McDonald House Charities
- Through advertisements throughout the hospital, such as in children's play areas, Starlight rooms, or wards
- Through connections or advertisements in follow up clinics
- By sending their family an invitation after discharge, where allowed

Establishing rapport and ground rules

Once you have made connections with some children and young people, you can start the co-design process. At the beginning, it is important to take time to develop rapport with the children and young people you work with, to help minimise power imbalances and ensure they feel safe and comfortable. It is also important to develop and agree on some ground rules together, so everyone knows the boundaries for safe and inclusive involvement.

Some things you might like to consider discussing include:

- Introducing all members of the team, including what their roles are
- Outlining the aims or goals of the session or activity
- Exploring together how to make the meeting space feel psychologically safe
- Discussing the importance of taking turns, showing respect and kindness, and valuing different opinions and ideas
- Explaining how the session will run, and what to do if anyone wants a break or would like to stop taking part
- Orienting children and young people to the space, including where the bathrooms are, where their parents are (if not in the room), what snacks or refreshments are available
- Playing some initial warm-up or get-to-know-you games to help children and young people feel comfortable with the other participants

Keeping it fun and engaging

Once you have developed sufficient rapport with the children and young people taking part, it's time to get started with seeking their ideas, thoughts, feedback, and suggestions for your study. A key aspect of working with children and young people is making sure the activities are fun and engaging, to maintain their interest.

For in person meetings, it's important to be creative and offer a range of different activities or modes of engagement. You might like to consider having different stations for different topics or activities or to involve games, stickers, art activities, or other creative methods for children and young people to share their ideas. For older children or young people, or those with alternative communication needs, you might also like to consider using digital technologies to facilitate engagement and involvement. It's also important to factor in regular breaks for snacks, playing outside, or using digital devices.

For on-line or virtual meetings, you can consider using collaborative online platforms such as Canva, Lucid Charts, Miro Boards, Shared Whiteboards, or other methods to support group co-creation and sharing of ideas and suggestions. Make sure you offer support and training for children and young people to sign up for and use these online tools, if you use them. When working online, you should also consider children and young people's preferences for having their camera on or off, and how this might impact your group dynamics and activities.

What do I do with the parents?

Often, children and young people are accompanied to co-design activities (both in person or online) by a parent, guardian, or another carer. How these parents or adults are included in the activities will depend on each child and their preferences. You should always ask each child or young people whether they would like their adult to remain with them and respect their choice.

For in-person meetings, it's helpful to plan for the presence of adults both within and separate to the space you are meeting in. Within the meeting space, you might set up some chairs and waiting areas at the back of the room, and where possible, offer tea, coffee, or refreshments for parents and carers, or offer vouchers they can use to purchase refreshments from a local café or cafeteria. In addition, many parents and carers may prefer to use the opportunity to engage in their own work, so it's helpful to provide a quiet space with desks, chairs, and access to power and internet facilities that they can work from, as well as considering a private space where they can catch up on phone calls or zoom meetings.

If parents and carers remain present in the room, it's important to consider whether and how parents and carers are able to be involved in the discussions and activities, and what impacts this may have on the children and young people's ability to engage freely. It is also useful to have a separate waiting area available for parents, adjacent to the main activity space. You might like to consider also running some focus groups or activities for parents, to gain their insights into the project.

What support and resources should I consider?

When planning to work with children and young people, there are several supports and additional resources you should have available. These might include:

Additional researchers: In general, children and young people will need more support and encouragement to engage in activities than adults will. This is especially true when you are working with younger children or children with different developmental or communication abilities, who may need support to communicate their ideas verbally or in writing. Ideally, you should plan for at least one researcher to support each group activity, and one additional researcher to coordinate and keep things on track. However, try to make sure you don't have too many adults, as this can also be overwhelming for children and young people.

Carers: Some children and young people will have additional support needs for things like communication, personal hygiene and toileting, emotional support, or for eating and drinking. It's important to ask parents what support needs their children have, and either ensure you can facilitate a known caregiver to support the child, or you have additional, appropriately trained caregiving supports available. This will help to ensure your activities are inclusive and enable participation from all children and young people, regardless of their needs.

Note taking and record keeping: Make sure you consider how you will record the meeting, including who attended, what was said, and whether you will take and keep photos of the participants, their notes or art or other created documents, and how this will be securely stored and destroyed once it is no longer needed. This information should be clearly communicated to the children and their young people, and their parents, carers, or guardians.

Food and snacks: It's a good idea to offer a variety of food, drink, and snacks at in person meetings. This helps demonstrate your care and attention to the needs of children and young people and also provides a good opportunity for a break. Before your activity, check in with children and young people and their parents, carers, or guardians for any food allergies or special needs.

Time out spaces and activities: Many children and young people get easily tired or overwhelmed by activities and need breaks to rest and meet sensory needs. Where possible, try to arrange a time out space, where children and young people can safely remove themselves and take a break. These spaces might include resources such as feelings cards, fidget and sensory toys, puzzles, colouring activities, play dough, Lego sets, reading books, and soft toys.

Recognition and remuneration

Just like adults, children and young people should be appropriately remunerated for their time and engagement. However, this needs to be carefully considered so that it is not coercive towards participation, and so that aligns with legal requirements around the engagement of children and young people in paid work. In general, most organisations recommend the provision of gift vouchers for children and young people. Many children and young people do not have their own bank accounts, and the provision of gift cards helps to ensure the remuneration directly reaches them. At present, there are no guidelines on appropriate remuneration amounts for children and young people involved in research design. Instead, you might like to consider the adult remuneration guidelines provided by Monash Partners or the Australian Clinician Trials Alliance as a starting place. It may also be necessary to consider the age of the child or young person when exploring remuneration, as this may sometimes be proportionate to the age of the child or young person.

In addition, children and young people can be recognised for their involvement in other ways. This might include:

- Provision of certificates of involvement
- Written references from the research team to support university or volunteering roles
- Opportunities to co-author publications, such as academic publications, reports, or other written dissemination opportunities
- Opportunities to co-present the research or experiences at events and conferences
- Photos (named or anonymous) and contributions to newsletters

In addition, consideration needs to be given to ensuring that children, young people, and their families are not out-of-pocket for their involvement. You should try to cover reasonable costs of attending, such as:

- Parking costs
- Travel costs, such as public transport fees or overnight accommodation, if required
- Communication costs, such as prepaid mobile phone or data cards
- Necessary costs for a support person, such as a parent or carer

Where possible, offer to book and pay for these costs in advance, so that children and young people are not out-of-pocket. If this is not possible, make sure you share information on how to be reimbursed, and ensure this is processed as quickly as possible.

Ending the project or engagement activity

Thinking through your exit strategy for when the project or engagement activity comes to an end is an important aspect of working with children and young people. It's important to prepare the children and young people in advance for a project's conclusion, so they are aware of the end-date. This is especially important if you have worked with a group of children and young people over a prolonged period of time. Normally, an exit strategy would involve feeding back about how children and young people's involvement has shaped, influenced or improved the research, and how their involvement has or will be used moving forward. This might occur informally at the end of the last meeting, or more formally through written, recorded, or other summaries.

In addition, it's important to consider how you will evaluate your engagement with children and young people to design and conduct research. This can be done in a number of ways, including formal surveys or feedback groups or informal discussions and written feedback. You might like to ask someone else to collect the feedback and evaluations for you or provide a way for children and young people to share their thoughts and experiences anonymously. This way, you can try to minimise power imbalances to make sure children and young people feel safe to provide honest feedback on their experiences.

Further resources and reading

Australian Clinical Trials Alliance Toolkit: https://involvementtoolkit.clinicaltrialsalliance.org.au/

Partnering in research: Guidelines for engaging children and young people as consumer research partners: https://healthy-trajectories.com.au/wp-content/uploads/2024/11/Guidelines-for-Engaging-Young-People_1Oct2024.pdf

Involving children and young people as advisors in research – top tips and essential key issues for researchers. https://arc-nenc.nihr.ac.uk/wp-content/uploads/2021/07/NIHR-Involving-children-and-young-people-as-advisors-in-research-April-2021.pdf

Top tips for involving children and young people in research: https://healthinnovation-em.org.uk/images/resource-hub/PPI%20documents/Top_tips/NIHR_Top_Tips_for_Involving_Children_and_Younp_People_in_Research.pdf

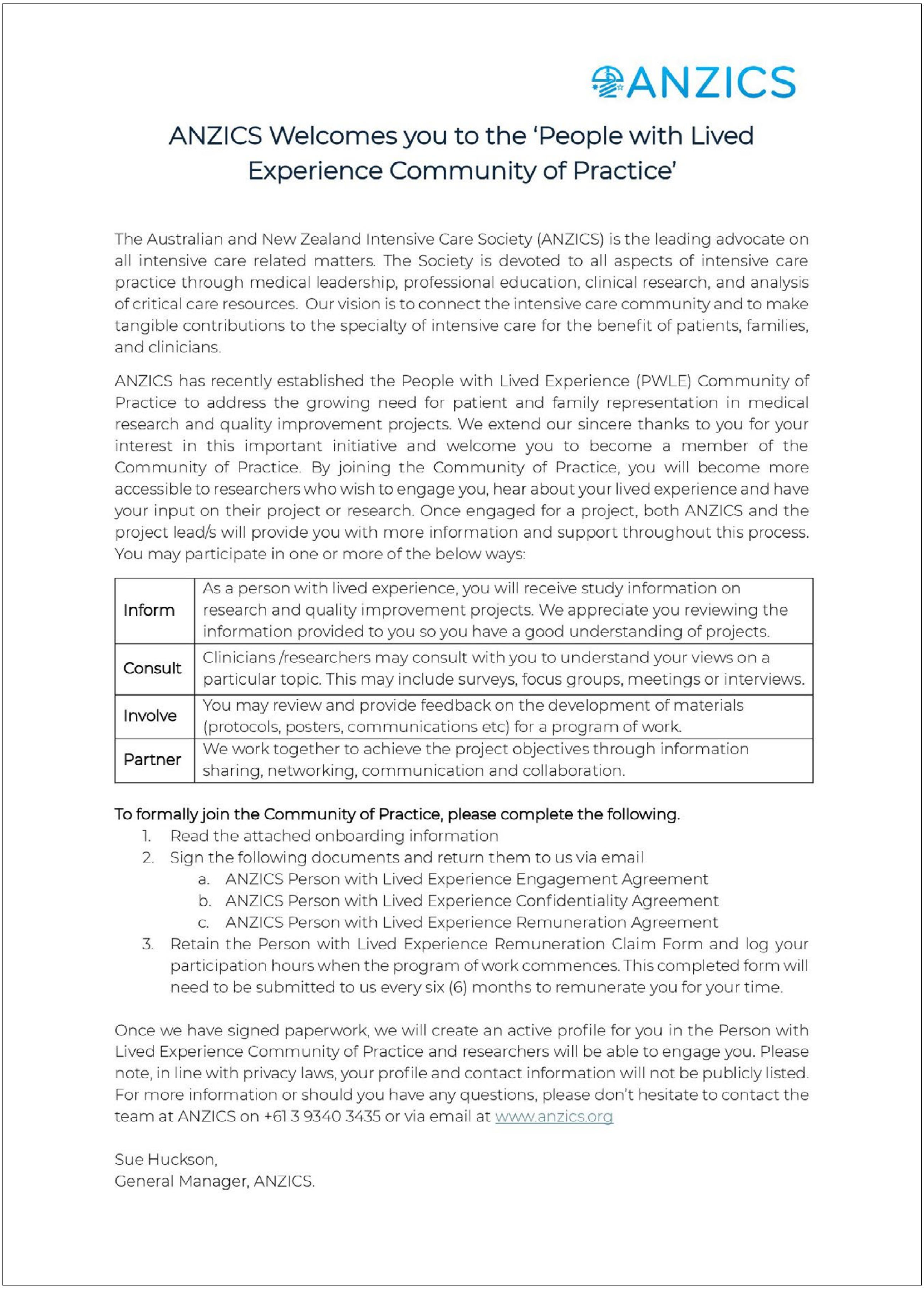
European Young Persons Advisory Group Network eYPAGnet toolkit: https://eypagnet.eu/toolkit/

Appendix E: Practical Resources to Assist Patient and Family Engagement Efforts

Appendix E.1: ANZICS People With Lived Experience Engagement Pack

The following documents were co-designed with people with lived experience of critical illness. They are used by ANZICS when working with lived experience experts. Other organisations are permitted to use this content to guide the creation of their own documents, but they should clearly adapt the documents to their local context or setting.

1. Welcome letter
2. Position description
3. Engagement contract
4. Confidentiality agreement
5. Remuneration agreement
6. Log of hours
7. Expense claim form
8. Expression of interest form



ANZICS

ANZICS Welcomes you to the 'People with Lived Experience Community of Practice'

The Australian and New Zealand Intensive Care Society (ANZICS) is the leading advocate on all intensive care related matters. The Society is devoted to all aspects of intensive care practice through medical leadership, professional education, clinical research, and analysis of critical care resources. Our vision is to connect the intensive care community and to make tangible contributions to the specialty of intensive care for the benefit of patients, families, and clinicians.

ANZICS has recently established the People with Lived Experience (PWLE) Community of Practice to address the growing need for patient and family representation in medical research and quality improvement projects. We extend our sincere thanks to you for your interest in this important initiative and welcome you to become a member of the Community of Practice. By joining the Community of Practice, you will become more accessible to researchers who wish to engage you, hear about your lived experience and have your input on their project or research. Once engaged for a project, both ANZICS and the project lead/s will provide you with more information and support throughout this process. You may participate in one or more of the below ways:

Inform	As a person with lived experience, you will receive study information on research and quality improvement projects. We appreciate you reviewing the information provided to you so you have a good understanding of projects.
Consult	Clinicians /researchers may consult with you to understand your views on a particular topic. This may include surveys, focus groups, meetings or interviews.
Involve	You may review and provide feedback on the development of materials (protocols, posters, communications etc) for a program of work.
Partner	We work together to achieve the project objectives through information sharing, networking, communication and collaboration.

To formally join the Community of Practice, please complete the following.

1. Read the attached onboarding information
2. Sign the following documents and return them to us via email
    a. ANZICS Person with Lived Experience Engagement Agreement
    b. ANZICS Person with Lived Experience Confidentiality Agreement
    c. ANZICS Person with Lived Experience Remuneration Agreement
3. Retain the Person with Lived Experience Remuneration Claim Form and log your participation hours when the program of work commences. This completed form will need to be submitted to us every six (6) months to remunerate you for your time.

Once we have signed paperwork, we will create an active profile for you in the Person with Lived Experience Community of Practice and researchers will be able to engage you. Please note, in line with privacy laws, your profile and contact information will not be publicly listed. For more information or should you have any questions, please don't hesitate to contact the team at ANZICS on +61 3 9340 3435 or via email at www.anzics.org

Sue Huckson,
General Manager, ANZICS.

ANZICS Person with Lived Experience Position Description

Position Purpose

The Australian and New Zealand Intensive Care Society is devoted to all aspects of intensive care. Our vision is to connect the intensive care community and to make tangible contributions to the specialty of intensive care for the benefit of patients, families, and clinicians. As a member of the Community Engagement Registry, your role will help us capture the voice of patients and carers, allow us to listen to your unique and crucial points of view and help us incorporate these into decision-making.

Levels of engagement

Researchers, registry users and clinicians may ask for you to be involved in some or all of the levels outlined below.

Inform	As a person with lived experience, you will receive study information on research and quality improvement projects.
Consult	Clinicians /researchers may consult with you to understand your views on a particular topic. This may include surveys, focus groups, meetings or interviews.
Involve	You may review and provide feedback on the development of materials (protocols, posters, communications etc) for a program of work.
Partner	We work together to achieve the project objectives through information sharing, networking, communication and collaboration.
Lead	You are actively involved in leading strategy and governance of all projects, studies and manuscript preparation.

ANZICS

Roles & Responsibilities:

- Actively communicate with researchers and project leads throughout the project or body of work.
- Actively participate in surveys. Interviews and other activities as required
- Undertake background reading when required
- Declare any potential conflicts of interest if/as they arise.
- Maintain confidentiality and privacy.
- Maintain a log of your hours of participation, get this signed by your project lead and retain any receipts for Taxation claims.

Our Requirements:

Each Person with Lived Experience is required to sign an Engagement Agreement, Confidentiality Agreement and Remuneration Agreement to become member of the Community Engagement Registry. These agreements outline appropriate conduct with others, the need to maintain confidentiality and declare any conflicts of interest. A breach of any of these may result in your involvement with the Registry being terminated.

Qualifications:

There are no set educational or professional requirements for this role. We would like a diverse range of participants from different professions and varying levels of education and ethnicity to reflect the wider community.

Equality & Inclusion:

ANZICS is an equal opportunity employer committed to providing a workplace free from any unlawful discrimination, harassment or bullying. This role is open to people who have previously been a patient in the Intensive Care Unit or had a loved one admitted to the Intensive Care Unit in Australia or New Zealand. We particularly encourage Persons with Lived Experience from minority groups and those that are often underrepresented to participate. If you have any special requirement for your active participation please let us know in the EoI form. This will not exclude you, rather allow us to better support you in the role.

Term:

This role does not have a set term. Your involvement is voluntary and ongoing at your own discretion. As a Person with Lived Experience, you can leave the Community of Practice at any time. ANZICS does however, review its policies and practices every three years. As such we may update or refine our paperwork and aspects of the role. This will always be communicated to you should changes or improvements need to be made.

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ANZICS People with lived experience Community of Practice Engagement Agreement

Dear <insert full name of participant>

Thank you for your expression of interest in joining the Australian and New Zealand Intensive Care Society (ANZICS) People with lived experience Community of Practice. We would like to welcome you to the Community of Practice which will allow Researchers and Registry users to collaborate with you to improve our healthcare system for all.

As a registered Person with Lived Experience, you are agreeing to commit to attend meetings, actively participate, ask questions and contribute positively to research and quality improvement projects. Whilst participating in various projects, you agree to show all participants respect and consideration. Similarly, as a consumer, you agree to represent the average person likely to be in your position rather than your own personal vested interests. Should a conflict of interest arise upon your engagement on a project, you need to declare this financial or personal conflict of interest to ANZICS and the project lead immediately.

ANZICS acknowledges its commitment to supporting the needs of people with lived experience. ANZICS, our partners and researchers must comply with the *Information Privacy Act 1998* and the *Health Records Act 2001*. This means your personal details will not be shared beyond the core project you have agreed to participate in without your prior knowledge and consent. You will be provided with the opportunity for an exit interview upon completion of each project should you wish and support for emotional distress or concerns at any time should they be triggered as a result of your participation.

Participant Full Name: ________________________

Participant Signature: ________________________

Date Signed: ________________________

ANZICS OFFICE USE ONLY

Approved by:	
Date:	
Signature	

PLEASE KEEP A COPY OF THIS AGREEMENT FOR YOUR RECORDS

ANZICS

Person with Lived Experience Community of Practice Confidentiality Agreement

Dear < insert full name of participant >

As a Person with Lived Experience, you may hear, see or be given confidential information as part of your advocacy role. This may include details about research findings, finances, or may include personal information about patients, their families or healthcare staff.

In line with the *Australian Privacy Act (1988*) and *New Zealand Privacy Act (2020)*, during and after your involvement as a PWLE, all confidential information must be treated in the strictest confidence. You must not share or discuss personal information unless the project lead or principal investigator confirms that it is acceptable and lawful to do so.

By signing this Confidentiality Agreement, you agree to:

- Respect the need for confidentiality and take reasonable steps to ensure the appropriate disposal of sensitive, confidential or embargoed material.
- Not disclose the content of any project, including research results and findings, before public release and agree to check with the project lead/principal investigator if unsure about a confidentiality concern.
- Not discuss or share sensitive or personal information outside of project meetings and activities.
- Participate in meetings and other activities as appropriate to support engagement with the project, and represent yourself and community in meetings and activities and not the views of any particular organisation.
- Disclose any known or perceived conflict of interest.

I ______________________________ (print name) understand this confidentiality agreement applies to me both during and after my participation as a Person with Lived Experience representative and acknowledge that a breach of these terms may result in my termination from the ANZICS Person with Lived Experience Community of Practice.

Participant Full Name: ____________________

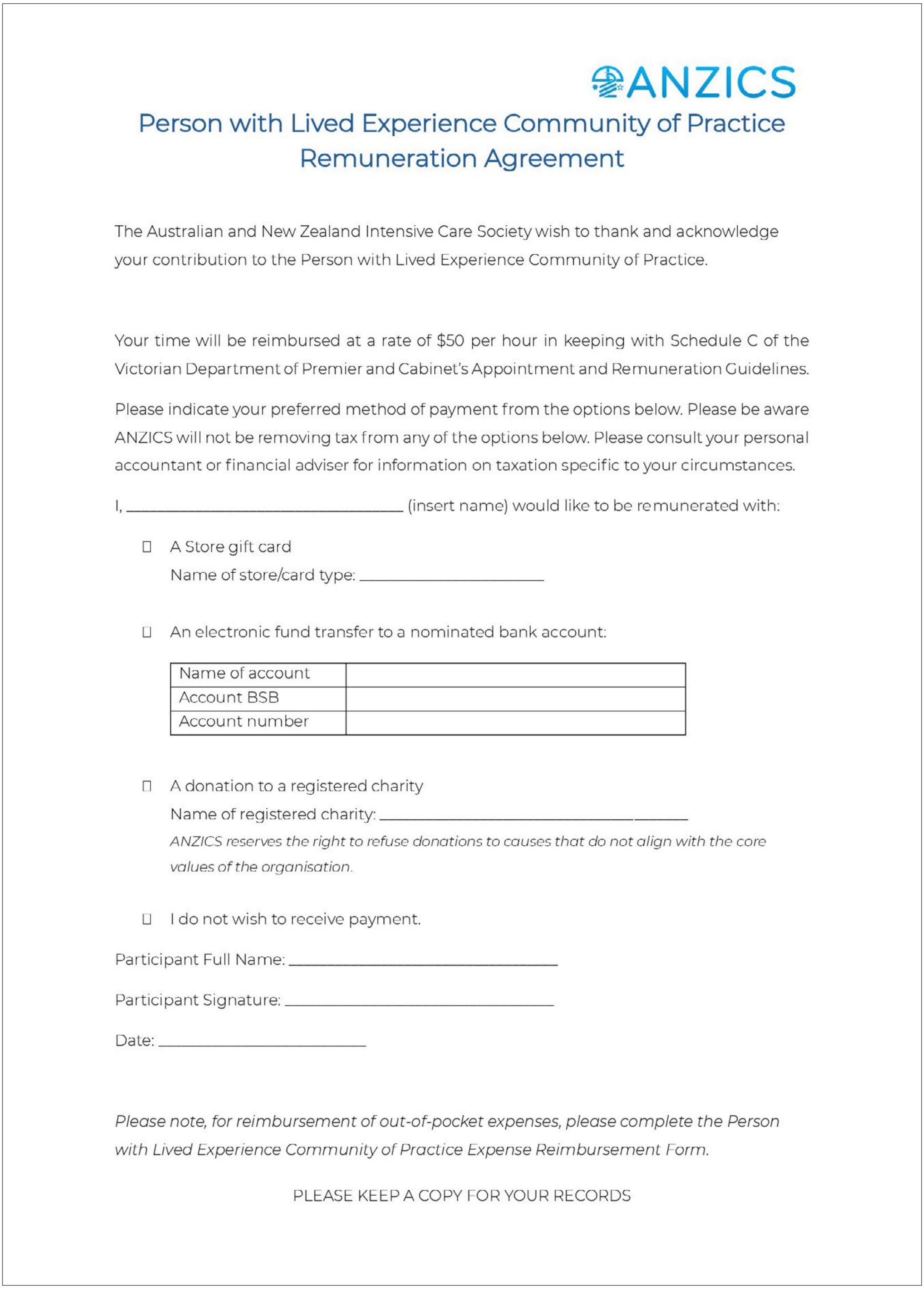
Participant Signature: ____________________

Date Signed: ____________________

ANZICS OFFICE USE ONLY

Approved by:	
Date:	
Signature	

PLEASE KEEP A COPY FOR YOUR RECORDS



ANZICS

Person with Lived Experience Community of Practice Remuneration Agreement

The Australian and New Zealand Intensive Care Society wish to thank and acknowledge your contribution to the Person with Lived Experience Community of Practice.

Your time will be reimbursed at a rate of $50 per hour in keeping with Schedule C of the Victorian Department of Premier and Cabinet's Appointment and Remuneration Guidelines.

Please indicate your preferred method of payment from the options below. Please be aware ANZICS will not be removing tax from any of the options below. Please consult your personal accountant or financial adviser for information on taxation specific to your circumstances.

I, ________________________________ (insert name) would like to be remunerated with:

☐ A Store gift card
Name of store/card type: ____________________

☐ An electronic fund transfer to a nominated bank account:

Name of account	
Account BSB	
Account number	

☐ A donation to a registered charity
Name of registered charity: ___________________________________
ANZICS reserves the right to refuse donations to causes that do not align with the core values of the organisation.

☐ I do not wish to receive payment.

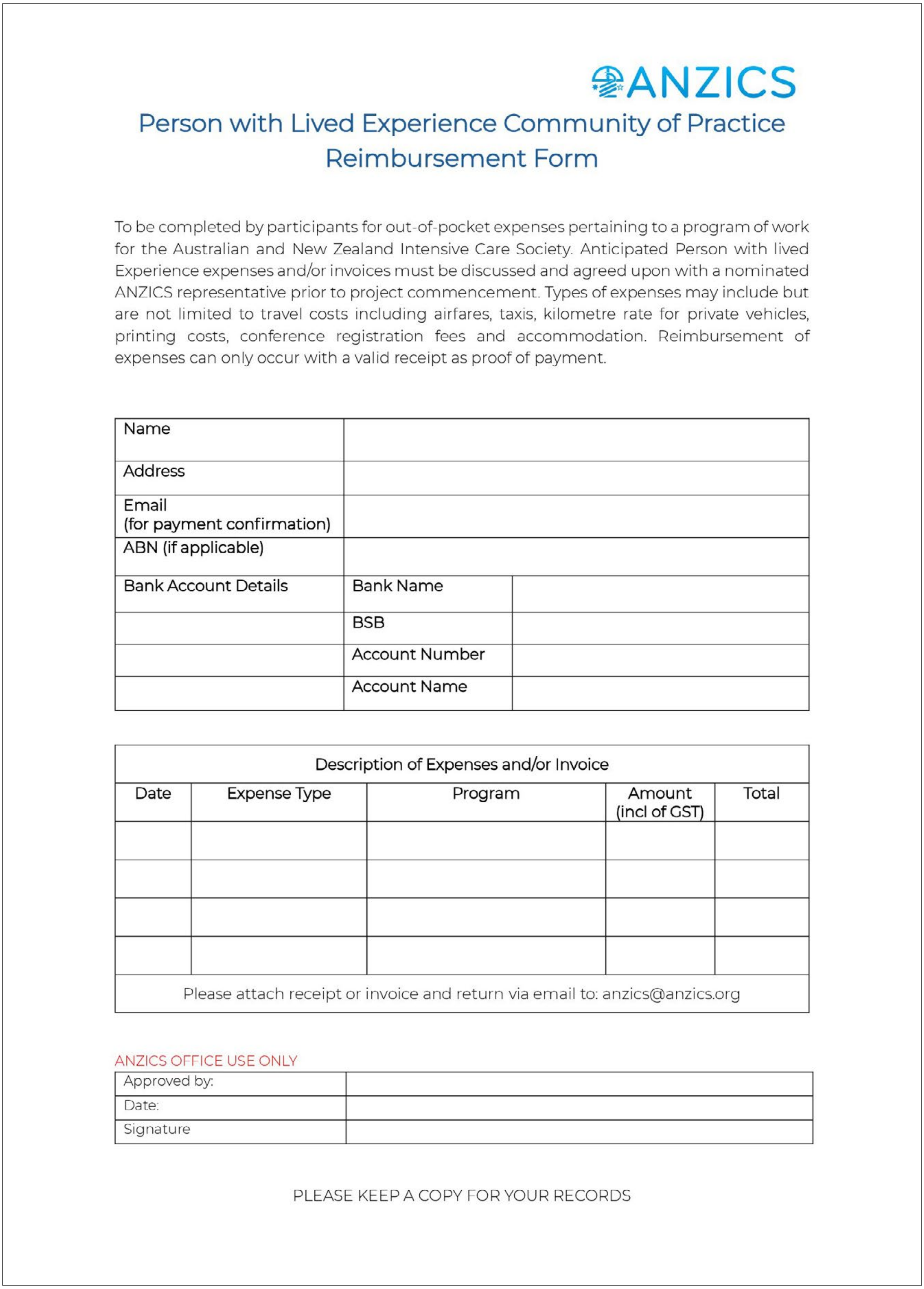
Participant Full Name: ______________________________

Participant Signature: ______________________________

Date: _______________________

Please note, for reimbursement of out-of-pocket expenses, please complete the Person with Lived Experience Community of Practice Expense Reimbursement Form.

PLEASE KEEP A COPY FOR YOUR RECORDS



ANZICS

Person with Lived Experience Community of Practice Reimbursement Form

To be completed by participants for out-of-pocket expenses pertaining to a program of work for the Australian and New Zealand Intensive Care Society. Anticipated Person with lived Experience expenses and/or invoices must be discussed and agreed upon with a nominated ANZICS representative prior to project commencement. Types of expenses may include but are not limited to travel costs including airfares, taxis, kilometre rate for private vehicles, printing costs, conference registration fees and accommodation. Reimbursement of expenses can only occur with a valid receipt as proof of payment.

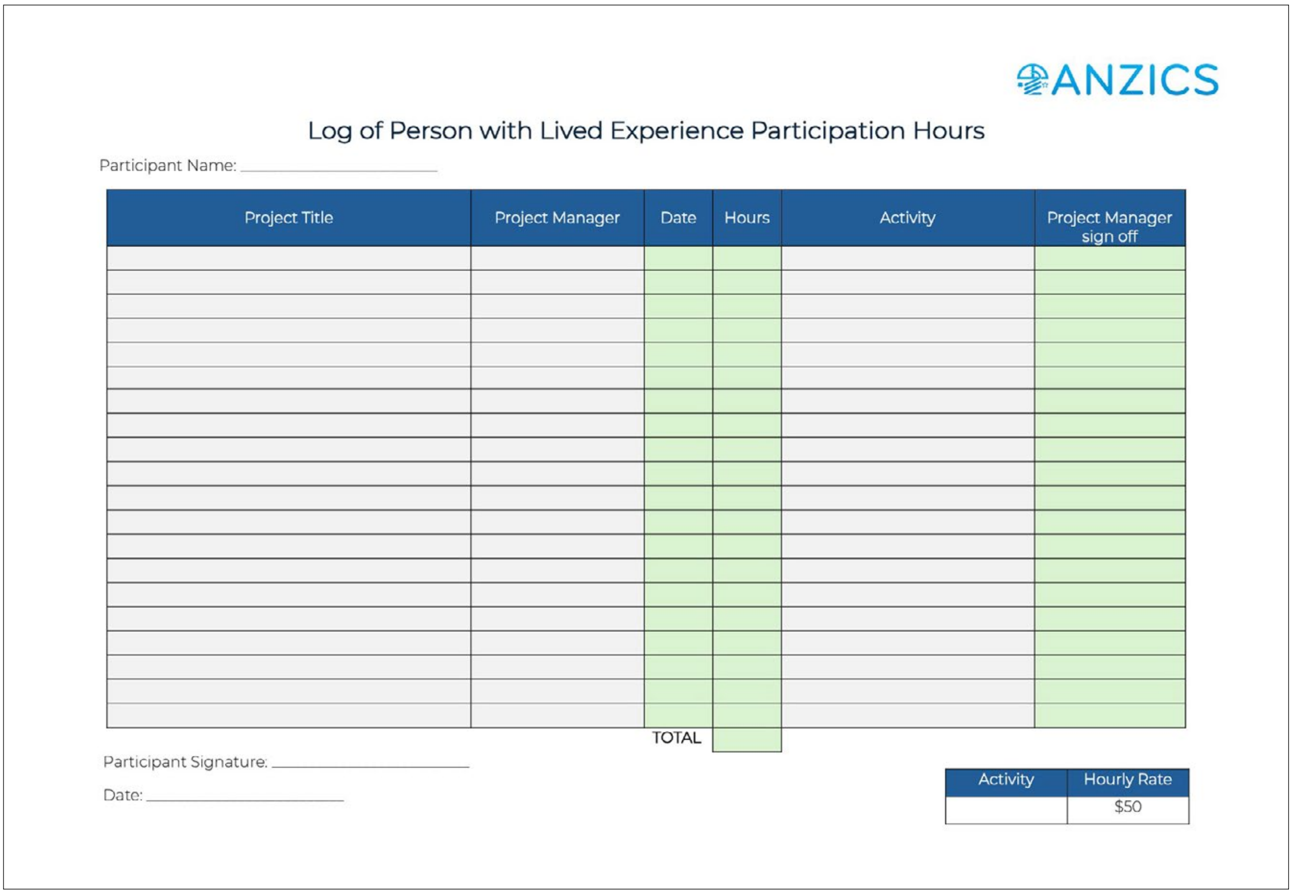
Name		
Address		
Email (for payment confirmation)		
ABN (if applicable)		
Bank Account Details	Bank Name	
	BSB	
	Account Number	
	Account Name	

Description of Expenses and/or Invoice				
Date	Expense Type	Program	Amount (incl of GST)	Total
Please attach receipt or invoice and return via email to: anzics@anzics.org				

ANZICS OFFICE USE ONLY

Approved by:	
Date:	
Signature	

PLEASE KEEP A COPY FOR YOUR RECORDS



ANZICS

Log of Person with Lived Experience Participation Hours

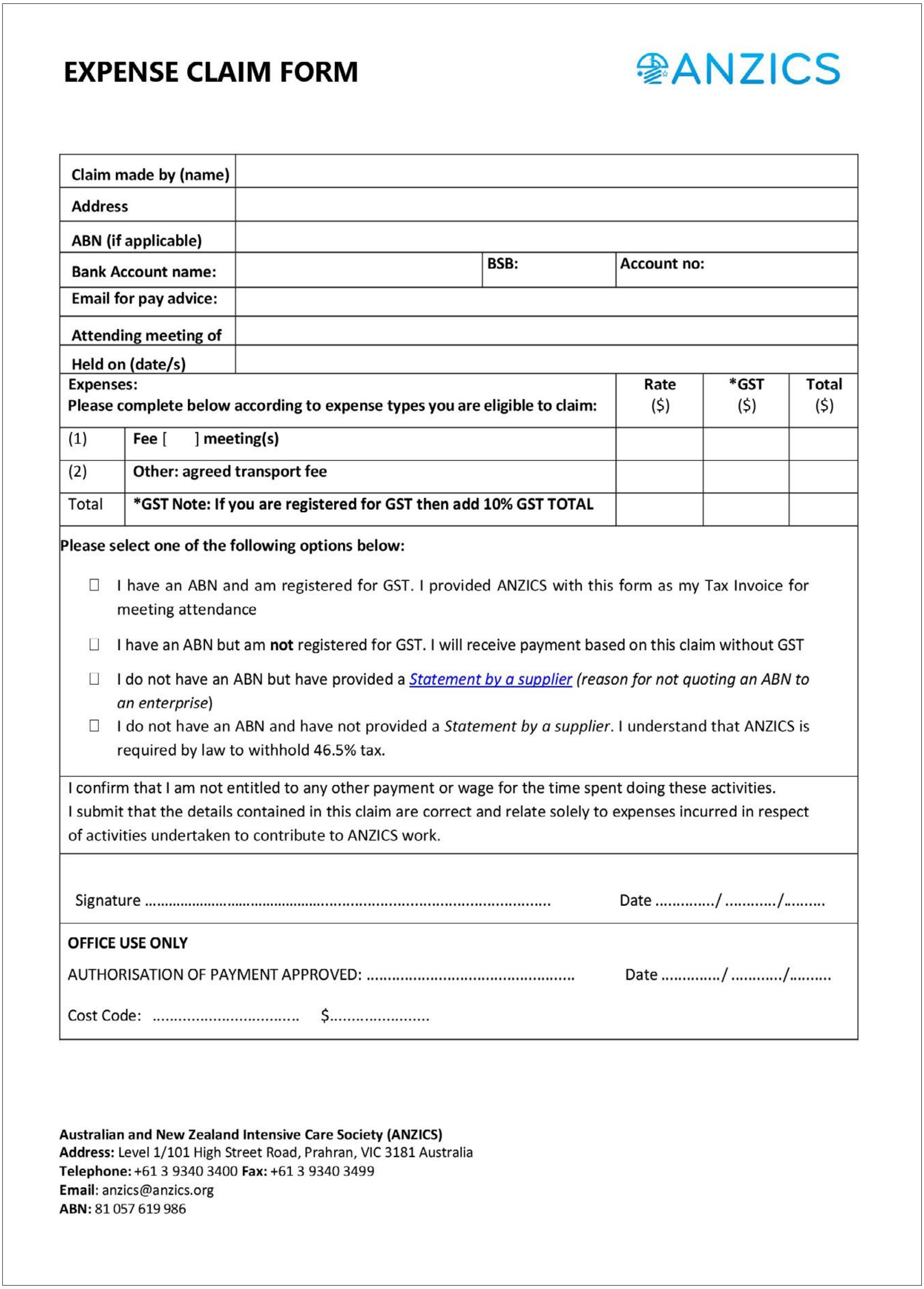
Participant Name: ____________________

Project Title	Project Manager	Date	Hours	Activity	Project Manager sign off
		TOTAL			

Participant Signature: ____________________

Date: ____________________

Activity	Hourly Rate
	$50



EXPENSE CLAIM FORM

ANZICS

Claim made by (name)			
Address			
ABN (if applicable)			
Bank Account name:		**BSB:**	**Account no:**
Email for pay advice:			
Attending meeting of			
Held on (date/s)			

		Rate ($)	***GST** ($)	**Total** ($)
Expenses: **Please complete below according to expense types you are eligible to claim:**				
(1)	**Fee** [ ] **meeting(s)**			
(2)	**Other: agreed transport fee**			
Total	***GST Note: If you are registered for GST then add 10% GST TOTAL**			

Please select one of the following options below:

- ☐ I have an ABN and am registered for GST. I provided ANZICS with this form as my Tax Invoice for meeting attendance
- ☐ I have an ABN but am **not** registered for GST. I will receive payment based on this claim without GST
- ☐ I do not have an ABN but have provided a *Statement by a supplier (reason for not quoting an ABN to an enterprise*)
- ☐ I do not have an ABN and have not provided a *Statement by a supplier*. I understand that ANZICS is required by law to withhold 46.5% tax.

I confirm that I am not entitled to any other payment or wage for the time spent doing these activities.
I submit that the details contained in this claim are correct and relate solely to expenses incurred in respect of activities undertaken to contribute to ANZICS work.

Signature .... Date ..../ ..../..........

OFFICE USE ONLY

AUTHORISATION OF PAYMENT APPROVED: .... Date ..../ ..../..........

Cost Code: .... $.......................

Australian and New Zealand Intensive Care Society (ANZICS)
Address: Level 1/101 High Street Road, Prahran, VIC 3181 Australia
Telephone: +61 3 9340 3400 **Fax:** +61 3 9340 3499
Email: anzics@anzics.org
ABN: 81 057 619 986

Appendix E.2: Other Helpful Resources

The following resources have been developed by organisations other than ANZICS. While this list is not exhaustive, it can serve as a helpful tool for researchers who are planning to engage with patients and families.

Helpful statements and toolkits

1. NHMRC Statement on Consumer and Community Involvement in Research

   This statement aims to guide research institutions, researchers, consumers and community members in the active involvement of consumers and community members in all aspects of health and medical research. Access here: https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research

2. Australian Institute of Aboriginal and Torres Strait Islander Studies (AITSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research

   Access here: https://aiatsis.gov.au/sites/default/files/2020-10/aiatsis-code-ethics.pdf

3. Te Ara Tika Guidelines for Māori Research Ethics

   Access here: https://www.hrc.govt.nz/resources/te-ara-tika-guidelines-maori-research-ethics-0

4. Australian Clinical Trials Alliance (ACTA) and Clinical Trials: Impact & Quality (CT:IQ) Consumer Involvement & Engagement Toolkit

   This toolkit provides practical advice for researchers and research organisations wishing to conduct patient-centred clinical trials. Access here: https://involvementtoolkit.clinicaltrialsalliance.org.au/

5. Victorian Comprehensive Cancer Centre Consumer Engagement Toolkit https://vcccalliance.org.au/consumer-engagement/resources/

6. Sharing power in global health research: an ethical toolkit for designing priority-setting processes that meaningfully include communities

   An ethical toolkit and effective project planning aid to use before performing research priority-setting. It aims to create more inclusive processes that are less likely to reinforce hierarchies of privilege and subordination. Access here: https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-021-01453-y

7. Research Education and Training Program RETProgram Education Module: Consumer and Community Involvement in Health Research

   This free online interactive course explains community participation and engagement in research. Access here: https://www.retprogram.org/training/consumer-and-community-involvement-in-health-research

8. The Children's Intensive Care Research Program (ChIRP) consumer involvement resources. Access here: https://child-health-research.centre.uq.edu.au/research/childrens-intensive-care

Existing guidelines on remuneration and reimbursement of healthcare lived experience experts

1. Health Consumers NSW. Access here: https://hcnsw.org.au/training-resources/resources/remuneration-and-reimbursement-of-health-lived experience experts/
2. Victorian Comprehensive Cancer Centre Alliance. Access here: https://vcccalliance.org.au/consumer-engagement/resources/pages/consumer-remuneration/
3. Monash Partners. Access here: https://monashpartners.org.au/wp-content/uploads/2025/02/Payment-Reimbursement-and-Recognition-Guidelines-3.pdf
4. Safer Care Victoria. Access here: https://www.safercare.vic.gov.au/support-and-training/partnering-with-lived experience experts/health-services/how-to-engage-a-consumer-representative
5. Victorian Department of Premier and Cabinet. Access here: https://www.vic.gov.au/guidelines-appointment-remuneration
6. Australian Clinical Trials Alliance. Access here: https://clinicaltrialsalliance.org.au/wp-content/uploads/2024/07/ACTA-Consumer-Reimbursement-and-Remuneration-Policy-v2.0.pdf
7. West Australian Health Translation Network. Access here: https://cciprogram.org/wp-content/uploads/sites/2/2024/05/CCIP-Honorarium-Guidelines-2024.pdf
8. Health Consumers Queensland. Access here: https://www.hcq.org.au/wp-content/uploads/2024/05/HCQ-Remuneration-Position-Statement-Effective-1-July-2024-V02.pdf
9. South Australia Health Sitting Fees and Reimbursement for External Individuals Policy. Access here: https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/about+sa+health/consumer+carer+and+community+engagement/consumer+carer+and+community+engagement
10. Tasmanian Health Senate. Access here: https://www.health.tas.gov.au/about/what-we-do/strategic-programs-and-initiatives/clinical-engagement/tasmanian-health-senate-remuneration-and-reimbursement-guidelines
11. Australian Capital Territory Consumer, Carer and Community Representative Reimbursement. Access here: https://www.act.gov.au/__data/assets/pdf_file/0009/2423655/Consumer-Carer-and-Community-Representative-Reimbursement-Policy-ACT-Health-Directorate.pdf
12. Te Whatu Ora. Access here: https://www.hqsc.govt.nz/assets/Consumer-hub/Consumer-opportunities/Te-Whatu-Ora-Reimbursement-Rates-for-Consumer-Engagement-v2.pdf
13. Te Tāhu Hauora Health Quality & Safety Commission. Access here: https://www.hqsc.govt.nz/resources/resource-library/policy-for-paying-lived experience experts-who-are-involved-health-quality-and-safety-commission-work/

Patient and family engagement training resources

1. Health Consumers NSW Health Consumer Representative Training. Access here: https://hcnsw.org.au/training-resources/training-courses/community-health-consumer-representative-training/
2. Western Australian Health Translation Network Consumer and Community Involvement Program. Access here: https://cciprogram.org/community-involvement/#training
3. Monash Partners Consumer and Community Involvement online modules – primarily designed to support the needs of researchers and healthcare professionals. Access here: https://monashpartners.org.au/education-training-and-events/cci/
4. Research Education and Training Program Consumer and Community Involvement in Health Research. Access here: https://www.retprogram.org/training/consumer-and-community-involvement-in-health-research
5. The Kids Research Institute Australia online courses for researchers and consumers. Access here: https://training.thekids.org.au/courses/

Consumer engagement organisations

1. European Young Person's Advisory Group Network (https://eypagnet.eu/toolkit/)
2. Consumer health forum Aotearoa (https://www.hqsc.govt.nz/consumer-hub/consumer-health-forum-aotearoa/)
3. Consumers Health Forum of Australia (https://www.chf.org.au/get-involved/consumer-engagement-opportunities)
4. Health Consumers NSW (https://hcnsw.org.au/health-consumer-organisations/why-health-consumer-engagement/)
5. Health Consumers Council WA (https://www.hconc.org.au/)
6. Health Care Consumers Association ACT (https://www.hcca.org.au/)
7. Health Consumers QLD (https://www.hcq.org.au/)
8. Health Consumers TAS (https://healthconsumerstas.org.au/)
9. Health Consumer Advocacy Network of South Australia (https://healthconsumercolab.com.au/)

Resources for cald patient and family engagement

1. A multicultural demographic profile of each Queensland Health Service District can be found at https://www.health.qld.gov.au/multicultural/health_workers/mc_profilehsd
2. The Department of Home Affairs provides up to date data on population and settlement. This data can be searched by local government area and by ethnic community. The data is available at: https://data.gov.au/data/dataset/settlement-reports
3. Engaging Queenslanders: An introduction to working with CALD communities www.getinvolved.qld.gov.au/engagement/guides/cald/cald.html and the information kit and factsheets available at www.qld.gov.au/web/community-engagement/guides-factsheets/cald-communities/factsheets.
4. Free short videos designed by the University of Melbourne to increase engagement in clinical trials, available in Italian, Mandarin, Vietnamese and English at https://vimeo.com/critcareunimelb
5. The Child Family Community Australia resource sheet is a directory of key organisations and resources for practitioners and service providers working with families and children from CALD backgrounds, available at: https://aifs.gov.au/resources/resource-sheets/key-organisations-working-culturally-and-linguistically-diverse-families.
6. Victorian Department of Health resources for working with CALD communities available at https://www.health.vic.gov.au/populations/improving-health-for-victorians-from-culturally-and-linguistically-diverse-backgrounds

Co-design toolkits and resources

1. The Point of Care Foundations UK – Experience Based Co-Design Toolkit https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/
2. King's College London and King's Fund Publication Donetto, S., Pierri, P., Tsianakas, V., & Robert, G. (2015). Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector. The Design Journal, 18(2), 227–248. https://doi.org/10.2752/175630615X14212498964312
3. Australian Healthcare and Hospitals Association Experience Based Co-design Toolkit.

   This toolkit provides a convenient reference to equip those working in the health sector with the tools and approaches to bring consumers and health workers together in an authentic and equal partnership to co-design care to deliver an improved experience. Available at: https://ahha.asn.au/experience-based-co-design-toolkit
4. Mark, S and P, Hagen (2020) Co-design in Aotearoa New Zealand: a snapshot of the literature, Auckland Co-design Lab, Auckland Council.

   Available at: https://knowledgeauckland.org.nz/media/1900/co-design-in-aotearoa-new-zealand-a-snapshot-of-the-literature-s-mark-p-hagen-tsi-june-2020.pdf
5. The Auckland Co-Design Lab Ngā Pāraha tools.

   A selection of tools developed and tested by the Auckland Co-Design Lab, available for free at: https://www.aucklandco-lab.nz/tools

List of Abbreviations

ABN	Australian Business Number
ACSQHC	Australian Commission on Safety and Quality in Health Care
ANZ	Australian and New Zealand
ANZICS	Australian and New Zealand Intensive Care Society
CALD	Culturally and Linguistically Diverse
CQR	Clinical Quality Registry
CORE	Centre for Outcome and Resource Evaluation
CTG	Clinical Trials Group
GRIPP2	Guidance for Reporting Involvement of Patients and the Public Version 2
IAP2	International Association for Public Participation
ICU	Intensive Care Unit
NHMRC	National Health and Medical Research Council
PFE	Patient and Family Engagement
PIC	Paediatric Intensive Care
PWLE	People with Lived Experience

Glossary of Māori terms

Hauora	Health and wellbeing
Hapū	Kinship group, clan, sub-tribe
Hui	Meeting (noun), to meet (verb)
Iwi	Extended kinship group, nation, tribe
Kai	Food
Kaitiakitanga	Guardianship, stewardship
Karakia	Prayers or incantations
Kaupapa	Topic, subject, matter for discussion, proposal, study
Koha	Gift
Kotahitanga	Collective benefit, unity, solidarity
Mana	Prestige, power, autonomy, influence
Manaakitanga	Hospitality, kindness, care, respect, reciprocity
Meihana Model	An assessment framework for health practitioners working with Māori patients
Pae Ora	Healthy Futures Act 2022
Rangatiratanga	Authority, sovereignty, self-determination
Tangata whenua	People of the land
Te Kāhui Raraunga	The Māori Data Governance Network
Te Mana Raraunga	The Māori Data Sovereignty Network
Te taha wairua	Spiritual health and wellbeing
Te Tiriti o Waitangi	The Treaty of Waitangi
Te Whare Tapa Whā	A Māori health model developed by Sir Mason Durie based on the concepts of family, physical, mental and spiritual health
Te Wheke	A Māori health model developed by Dr Rose Pere that describes total wellbeing
Tino rangatiratanga	Sovereignty/self-determination
Tikanga	Appropriate protocols
Whakapapa	Lineage, genealogy, connection to ancestors
Whānau	Family, extended family group
Whanaungatanga	Reciprocal relationships
Whakawhanaungatanga	The process of building reciprocal relationships

Further definitions can be found at Te Aka Māori Dictionary: https://maoridictionary.co.nz.

ANZICS