CENTRE FOR
Eye Research
Australia

Cerulea
Clinical Trials
CENTRE FOR EYE RESEARCH AUSTRALIA

Partnering with people with lived experience to co-design research: Best practice guide for staff and students

Acknowledgments

This best practice guide (the 'Guide') was developed by a Project Advisory Group. This group included Fleur O'Hare, the Consumer Involvement and Advocacy Lead at the Centre for Eye Research Australia (CERA), as well as independent collaborators with lived experience. These collaborators were people affected by eye conditions themselves, caregivers supporting someone with an eye condition, or individuals potentially impacted by eye conditions.

CERA and Cerulea Clinical trials ('the CERA group') would like to thank the Project Advisory Group for their considerable expertise and direction, and for their time to help produce this Guide.

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Introduction

What is lived experience and why is it important to research?

Lived experience refers to the unique insights and perspectives gained through personal encounters with health conditions, treatments or the healthcare system. In our context, it encompasses the first-hand knowledge and understanding people acquire by living with a specific eye condition, or being involved in the eyecare journey as a patient or caregiver. Lived experience doesn't just focus on an individual's clinical experiences. It also incorporates thoughts, emotions, challenges, coping mechanisms and overall journey as they navigate their eye-related experiences (see **Figure 1**).

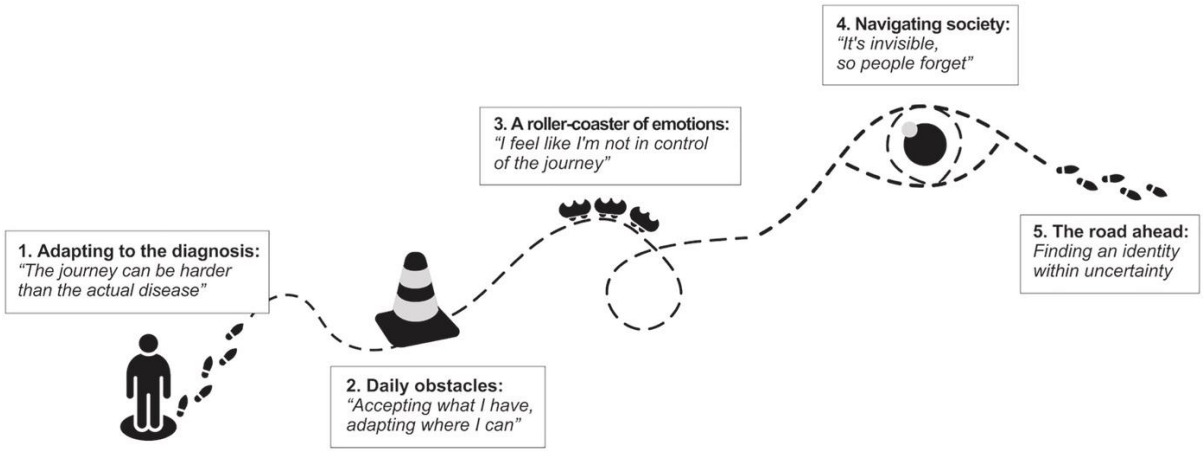


Figure 1. The 'experience journey' as perceived by people with eye conditions [Bakir et al., 2025]

The voices of people with lived experience of having an eye condition, and its impacts, are essential to enable the Centre for Eye Research Australia and Cerulea Clinical Trials ('the CERA group') to address real-world needs in research. CERA has committed at the Board level, and in its 2025–2030 strategic plan, to ensure that the involvement of people with lived experience, as members of a research team, is standard practice.

Partnerships between people with lived experience and researchers (encompassing staff at all levels as well as students) can help improve:

- The quality of our research

- The experience for patients, research participants, their carers and family members
- Research outcomes, making them more likely to be relevant, impactful and readily adopted in clinical practice.

The purpose of this best practice guide

This best practice guide (the 'Guide') has been developed in partnership with 'lived experience collaborators'. These are people who have lived experience of an eye condition and its impacts or potential impacts, including people who support or care for someone with an eye condition.

It is intended to help students and staff, including managers and researchers operating at all levels of the CERA group, to engage meaningfully with lived experience collaborators**.** This includes co-designing research questions, defining ethical boundaries, and interpreting research findings together to ensure relevance, respect and reciprocating insight.

This Guide aims to serve as a reference for researchers and staff to:

- Understand the importance of involving people with lived experience early, and ongoing, across their research project lifecycle
- Cultivate the skills to support effective partnerships, as well as be aware of how to address barriers to building collaborative relationships.

> **This Guide will evolve with changing needs and insights gained from ongoing lived experience collaborators we involve in research.**

How to use this Guide

The Guide has four chapters:

1. Why collaborate
2. How to collaborate
3. Communication and accessibility
4. The CERA group's Partnership Standard

Each chapter has a section with **reflective question**s and links to **further reading**.

There is a **glossary of key terms related to consumer involvement** on page 34. Information supplements are available in **appendices** at the end of this Guide.

Read and share this Guide with others in the team to strengthen a positive culture around lived experience partnerships.

Chapter 1: Why collaborate?

This chapter looks at the importance of first-hand experience and perspectives in enhancing the relevance of research.

It explains:

- The role of lived experience collaborators
- How we can partner with lived experience collaborators
- The benefits of research collaboration

What is the role of lived experience collaborators in research?

'Lived experience collaborator' is the term selected by our Consumer Advisory Group to reflect the role that people with lived experience have in our research. Lived experience collaborators are partners in the research. This is a different role to a 'research participant'.

> **Research participants contribute data to a project. Lived experience collaborators contribute ideas and insights to a project.**

Examples of participating in research include inviting people involved in the research to:

- Complete a survey
- Attend a focus group
- Take part in a clinical trial
- Provide retinal images or tissue that is analysed as part of a research study.

Engaging participants in research in these ways requires ethics approval.

In contrast, lived experience collaborators have an advisory or project steering role. They may collaborate with researchers in decision-making processes, from setting research agendas to designing protocols and interpreting findings. Effectively they are part of the research team. Rather than research being **for** people, research is conducted **with** or **by** them.

A note on terminology

The terms 'consumer', 'lived experience advisor' and 'lived experience research partner' are commonly used in the health and medical research sector. They are interchangeable with 'lived experience collaborator'.

In this Guide, we will use 'consumers' when referring to information at an organisation level, for example policy or governance. 'Lived experience collaborators' will be used when referring to individual contributors to research.

How we can partner with lived experience collaborators

Partnering with lived experience collaborators is fundamental for a medical research institute like the CERA group that undertakes translational research with real-world impact. It also aligns with our organisation's value of 'making a difference', that is, collaborating and sharing knowledge to create real-world impact. Consumer involvement is not just a supplementary goal; it is integral to researcher-initiated funding applications. For example, it reflects the expectations of major funding bodies like the Medical Research Future Fund (MRFF) and the National Health and Medical Research Council (NHMRC).

At the CERA group we have lived experience collaborators involved in our:

Advisory Committee: A panel of consultants who set the overarching strategy, governance policies and processes of consumer engagement for the CERA group. They have input into the strategic direction of the CERA group to ensure research aligns with broader consumer and community goals and expectations.

Partnership Program: People with lived experience who are involved as partners and collaborators in individual research projects. Their primary role is to elevate the voices and contributions of people with lived experience into the research process.

This represents a hybrid model that combines an advisory group for governance and strategy with a co-design partnership approach for operational and research-specific tasks. It ensures that our research not only meets high scientific standards but also resonates with the broader communities we serve. This includes people living with an eye condition, carers and funders.

Table 1 outlines different ways you can engage with people with lived experience or share your research with the community.

Table 1: Examples of different levels of engagement

Engagement	Description	Examples
High (co-lead)	Information sharing is two- way. Decisions are made with lived experience collaborators as lead investigators and steering advisors.	• Co-design and co-produce protocol • Key input into research plan and objectives • Co-presenter at conference • Advisory or steering role
Medium (collaboration, consultation)	Information sharing is two-way. Feedback is gathered and discussed to help inform research tasks or activities.	• Co-create research processes • Input into project proposal, study related documents, informed consent, grants • Member of project team • Co-author on publication
Low (inform)	Information sharing is one-way.	• CERA information forums • CERA and Cerulea websites • CERA newsletters • Information sheets

The CERA group is responsible for setting standards that support effective partnerships between researchers and people with lived experience. This Partnership Standard is discussed in Chapter 4.

The benefits of research collaboration

Partnering with lived experience collaborators involves ongoing dialogue and exchange of knowledge and learning. Lived experience collaborators are recognised as co-creators of research, sharing a common goal to make the research stronger.

Lived experience collaborators can:

- **Influence research priorities and direction:** Ensure research questions reflect what matters most to patients, research participants and communities. This creates greater relevance and impact.
- **Enhance research design and implementation**: Bring real-world perspectives into project design to ensure research addresses the needs and experiences of people with eye conditions and its impacts. This provides the balance needed to ensure research is both practically feasible and informed by diverse perspectives.
- **Facilitate effective communication:** Help develop strategies for communicating research findings in a way that improves understanding, trust and engagement with the vision community.
- **Advocate for participant needs**: Champion equitable research practices and advocate for the needs and concerns of participants in our research studies, and the wider community. This is especially important when developing a Plain Language Summary for publication with the research and during the dissemination of the research.
- **Promote collaboration and partnership**: Strengthen connections between researchers, clinicians and the public. This embeds trust and long-term sustainability into research practice.
- **Support policy development**: Contribute insights that inform policies and practices to ensure they are grounded in lived experience and aligned with the mission of the CERA group.

> **"Researchers need to realise that lived experience advisors will have some similarities to the participants of the eventual trial. So if the advisors don't understand the research design, the eventual participants in trials won't either."** – Consumer Program member.

Reflective questions

- How could you involve lived experience collaborators in your project?
- Can you accommodate two to three collaborators in your research team?
- How could lived experience perspectives shape your project?
- Have you reached out to research support services early and discussed your intention to involve lived experience collaborators in your project?

Further reading

From the literature

- **Barriers and enablers to consumer involvement in research and healthcare improvements: Perspectives from consumer organisations, health services and researchers in Melbourne, Australia** (Ayton et al., 2022).
- **Public involvement in Australian clinical trials: a systematic review** (Zirnsak et al., 2024).

Resources from other organisations

- **Collaborative Pairs program** (Consumers Health Forum of Australia)**.** A leadership development program that brings together a consumer, patient or community leader with a health service organisation, clinician or manager to develop new ways of working together.
- **Online information hub** (Australian Health Research Hub Alliance). Approaches and techniques for consumer involvement.

You can find more information on our intranet under 'consumer involvement', including an education video for both researchers and lived experience research partners.

Chapter 2: How to collaborate

This chapter aims to help researchers get started with engaging lived experience collaborators.

It explains:

- Moving from good intentions to good practice
- Partnership fundamentals
- The roles of researchers and lived experience collaborators in supporting effective partnerships
- How to negotiate common challenges and hurdles.

Moving from good intentions to good practice

Relationships between lived experience collaborators, researchers and the organisation must be built on three Rs: relevance, respect and reciprocity. Effective partnerships have open and honest communication, and respect each other's opinions, beliefs, values and culture.

> **Partnering with people with lived experience is about learning about the real-life impacts of having a chronic eye condition.**

A good place to start is to invite the collaborator to share their experience. Every person with lived experience will have a different story to tell. Hearing varied experiences will help you understand a wider perspective and the multiple impacts of living with that eye condition. Or, in the case of a parent or carer, the experience and perspectives of someone who is supporting a person with that eye condition.

Listening to these experiences is an opportunity to broaden the perspective of the research or factor in concerns or questions you may not have considered. Research designed and produced with lived experience collaborators means research outcomes are more likely to be relevant, appropriate and adopted, and to have real-world impact.

> **"Every person's experience will be different and listening to more than one of us will give the researcher a wider perspective"** – Consumer Program member.

Lived experience collaborators contribute by bringing an individual perspective rather than necessarily being representative of the views of many. Collaborating with a small group of people with lived experience is ideal.

Partnership fundamentals

There are 10 key principles that support effective collaboration at all levels of co-planning, co-designing, co-delivery and co-reviewing project materials (see **Figure 2**).

1. Involve people early

Collaborate from the planning stages of a research project. The earlier you start, the more people will understand and feel valued and part of the project. But it's never too late to start.

2. Build relationships

Invest time into building rapport and relationships. Effective partnerships are built on trust, respect and dignity.

3. Strive towards diversity

Involve people with diverse backgrounds and perspectives as this will improve the likelihood that your research will lead to treatments/services that reflect community needs.

4. Provide support

Provide access to appropriate resources, induction or training, and ensure out-of-pocket expenses are covered. Provide remuneration as either a gift card or hourly rate.

5. Develop skills

Continuously update your knowledge and skills in communication and accessibility practices. Be able to tailor your communications to suit individuals and their carers/trusted supporters as appropriate.

6. Manage expectations

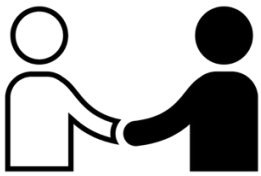
Work together to agree on roles, type and level of involvement that will suit both parties. This minimises the risk of frustration and disengagement. Be transparent about any constraints that impact what you can research and how.

7. Foster mutual respect

Give a 'voice' to, and respect, different ideas and perspectives. Acknowledge the contribution of those involved.

8. Strive for reciprocity

Ensure that all those involved in a project feel that they get something back. For example, provide ongoing project updates to them, and others, so there is appreciation of the impact of their contribution over time.



9. Be fair and transparent

Provide opportunities for involvement and contribution in an equitable and transparent manner.

10. Provide feedback

Share information willingly and in a language that everyone understands. For example, evidence of how your study benefited from their input is hugely rewarding for those involved.

Figure 2. 10 fundamentals for partnering with lived experience collaborators to co-design research

Roles in supporting effective partnerships

Partnerships mean that there are commitments and responsibilities on both sides.

The roles and responsibilities of individuals

Table 2 describes ways that both lived experience collaborators and researchers can contribute to a positive partnership experience.

Table 2. The roles of researchers and lived experience collaborators in supporting effective partnerships

What researchers can do	What can collaborators do
• Encourage questions and be willing to answer them. Use plain language. • Listen and discuss ideas and be open to new ideas. • Provide an orientation to both the CERA group and to the research project. • Manage power dynamics by ensuring collaborators feel valued and respected in meetings. Encourage equal input and time from all, not just the most vocal. • Provide clear information about the choices the collaborator has – how	• Ask questions. • Offer feedback about the experience being involved in the project team. • Take time to understand the project and issues to be discussed. • Ask for an orientation and/or training session about the organisation, the project and your role. • Be active in meetings and consultations. • Suggest wider consultation with the community if broader opinions need to be heard.

What researchers can do	What can collaborators do
many hours, which days, what tasks – at different time points. • Consider lived experience collaborators' opinions, preferences, values and priorities. • Encourage shared decision making. • Understand and respect culture, identities, beliefs and choices. • Adapt communications to each collaborator's preferred formats e.g. large print, accessible electronic format, short emails, phone calls over emails, assistance with videoconferencing, support to attend in-person meetings. • Give collaborators appropriate information on their roles and tell them how they add value to the research project. • Acknowledge and respect lived experience. • Look for and remove barriers to participation, including by having accessible and inclusive ways to communicate. Identify any gaps in training, education or support that would help you to engage effectively with lived experience collaborators.	• Respect the views of others. • Ask questions respectfully and offer constructive, balanced advice. • Ask for support to help engagement in meetings, including asking to have a carer present, and asking about accessibility and inclusive communication needs. • Ask how they can help plan and review services delivered by the CERA group. • Ask about opportunities to attend information sessions or forums to learn about specific issues. • Ask to meet with other lived experience representatives to build networks, get support and be more aware of issues affecting consumers, patients and participants across the CERA group.

The roles and responsibilities of the CERA group

As an organisation, it is our responsibility to:

- Train and support staff on how to partner with lived experience collaborators
- Develop a Partnership Standard and explain how this is operationalised (see Chapter 4)

- Offer opportunities for lived experience representatives to attend our events and expand their knowledge about the research we do
- Use feedback from lived experience collaborations to continually improve the process and engagement conditions at the organisation.

> **"The culture around, and the value placed on, involvement of people with lived experience in health and medical research comes from the top and spreads right across the organisation. This is needed to enable partnering with lived experience experts to occur."** – CERA's Consumer Advocacy and Involvement Lead.

Navigating solutions to common challenges

Bringing people together with different personalities, backgrounds, preferences and communication styles can be challenging. Like any relationship, time and effort is needed on both sides to make it work. It's also important for researchers to be aware of specific challenges that lived experience collaborators may face in their role. These include:

- Being the only lived experience collaborator within a larger project team, which can create a power imbalance. A minimum of two to three lived experience collaborators per project is recommended.
- Not being part of the early planning or start of a project.
- Not feeling welcome, valued, listened to, or able to ask questions.
- Not getting enough support or not being adequately prepared for the role, for example, not properly introduced or trained. It is reasonable for lived experience collaborators to say 'no' to being involved if there is inadequate support to do their role.
- Lacking the right information or tools to do the role well.
- Not having enough time to review documents e.g. previously unseen documents being tabled at meetings for endorsement.

Strategies to mitigate challenges

The strategies below will help you proactively prevent and respond to common challenges or situations that may arise.

Unintentional harm or distress

Managing unintentional harm or distress caused by lived experience collaborators sharing their stories is a crucial aspect of ethical research practice. Here's how to support both lived experience collaborators and yourself.

Pre-engagement preparation: Inform lived experience collaborators about potential emotional impacts before they share their story. Ensure that they understand they can choose and therefore control what to share. Inform them that there is no expectation around what to share, and that they can stop at any time.

Create a supportive environment: Establish a non-judgemental, respectful atmosphere for sharing. Set clear guidelines for respectful listening and confidentiality. Schedule breaks as needed to allow for emotional processing.

Active monitoring: Watch for signs of distress (e.g. body language, tone of voice) and check in with how a person is feeling during and after the sharing. It's important to offer post-sharing debriefing. This can be a phone call from you, or can be arranged through the Consumer Involvement and Advocacy Lead.

Immediate support strategies: Be prepared to pause the meeting or interaction and allow time for the person to recover. Acknowledge the situation and validate their emotions. For example: "We can see how this experience has had a significant impact on you. That would have been a challenging situation. Thank you for your willingness to share your experience with us".

Engage professional support: The Consumer Involvement and Advocacy Lead at the CERA group is available to provide further support to both lived experience collaborators and researchers. Support services can also be accessed through Human Resources.

Managing expectations

Balancing scientific rigour with lived experience perspectives is possible when there is clear communication around roles, purpose and what can and cannot be achieved.

It's important to make lived experience collaborators aware that while perspectives and ideas are encouraged, the research project is bound by constraints. This includes legal, moral, practical, statistical, financial, timeline and other obligations. The recommendations of the collaborators may not always be able to be implemented. This needs to be made clear so that they don't feel ignored if their suggestions are not actioned. Equally, it is important to feed back to lived experience collaborators how their input has contributed to the research on an ongoing basis.

Resolving conflict

Resolving conflict requires a multifaceted approach that emphasises clear communication, mutual understanding and collaborative problem-solving.

Tips to mitigate conflict:

- Establishing open dialogue through regular meetings and active listening
- Finding common ground by focusing on shared goals, and using structured conflict resolution models (see further reading section)
- Clearly defining roles and expectations
- Providing education to all team members, and implementing fair decision-making processes
- Encouraging perspective-taking, seeking external input when needed, and viewing conflicts as opportunities for growth
- Documenting agreements, providing necessary support, and continuously working on conflict prevention strategies.

Let lived experience collaborators know that they can raise their concerns with:

- The project team directly
- A 'buddy' in the project team
- Other members of our Consumer Program
- The Consumer Involvement and Advocacy Lead.

Feedback can also be provided via the evaluation survey that will be distributed to both consumer partners and researchers.

Supporting lived experience collaborators and their development

You can help lived experience collaborators to fulfill their roles and develop further by:

- Providing an orientation and induction session around the project and who the team are. This includes providing a copy of the CERA Code of Conduct or Cerulea Code of Conduct (as relevant) which outlines how we make our workplace safe, positive and inclusive.
- Arranging a coaching session with the Consumer Involvement and Advocacy Lead when the collaborators start their roles with your team
- Offering opportunities to brief and debrief around meetings and activities
- Organising payments that recognise and value their contributions
- Assigning a 'buddy' in the team or another consumer in CERA's consumer program to provide support
- Creating opportunities for lived experience collaborators to be considered for leadership roles and supporting them with leadership training
- Offering options for increasing their skills and knowledge in new areas, and providing accessible learning materials

- Ensuring timeframes are respectful and courteous, with information provided in accessible formats at least one week in advance of meetings.

Reflective questions

- Are you prepared to listen to divergent and opposing views to your own?
- Are you ready to accommodate more than one lived experience collaborator into your project team?
- How can you influence the way lived experience collaborators are treated and valued within your team?
- Are there things about the partnership that you would like to discuss with the Consumer Involvement and Advocacy Lead?
- Have you looked at some of the key resources and links below?

For more information, please view our education video and testimonials, co-designed by members of our consumer program, on Iris and webpage.

Further reading

Conflict management tools

- The **Interest-Based Relational (IBR) approach**, also known as **Interest-Based Negotiation**, is a conflict resolution method that focuses on understanding the underlying interests and needs of all parties involved.
- **Resolve Conflicts at Work Like a Pro** – Johnathan Westover, Human Capital Innovations.
- **Preventing and Managing Team Conflict** – Pamela Reynolds, Harvard University.

Resources from other organisations

- **Consumer Involvement and Engagement Toolkit** (Australian Clinical Trials Alliance). Covers information for both consumers and researchers.
- **Consumer Representatives Program resources** (Consumers Health Forum of Australia).
- **Consumer Involvement Toolkit** (Cancer Australia). A toolkit for health service organisations, which includes a self-assessment tool and steps to make a consumer engagement plan.
- **Key elements for effective involvement** (Australian Health Resource Hub).

Chapter 3: Communication and accessibility

Effective communication is the foundation of a strong partnership. Accessibility should be at the forefront of all communication and information exchange with lived experience collaborators.

This chapter covers:

- Best practice principles for effective communication
- The importance of information accessibility
- Accessibility considerations for partnering with lived experience collaborators
- Other factors that can impact participation.

Best practice principles for effective communication

This section outlines five best practice principles and practical strategies for embedding the principles into your practice.

1. Communicate in plain language

Plain language means avoiding medical jargon, or if used, explaining the terminology.

Tips for explaining research and medical terms:

- Ask lived experience collaborators to help rephrase terminology into simpler language
- Seek advice from colleagues on strategies that have helped them explain concepts or instructions in a more accessible way e.g. images, videos, plain language summaries
- Provide a glossary of terms specific to your research area
- Use AI software such as Co-pilot and Spark AI (endorsed by the University of Melbourne) to improve readability and simplify language.

See the further reading section for additional resources.

2. Actively listen and share speaking time

Key strategies for researchers:

- Allow enough time to hear what your lived experience collaborators have to say. Ensure that, like any member of your research team, they are made to feel like what they have to say is important and valued.
- Encourage diverse ideas and information exchange across all team members in project meetings.
- Ensure that no one person dominates discussions. It may be helpful to consider a **communication order** (see glossary) that you facilitate to ensure each person has an opportunity to share their thoughts.

3. Allow extra time

Researchers are used to fast paced decisions and actions. Lived experience collaborators may not be familiar with this environment and pace. They may also want to spend time building a relationship with you before they share their experiences and thoughts.

What 'allowing extra time' might look like in practice:

- Give people time to formulate their thoughts and communicate them. Involve family members or trusted supporters in the process as needed
- Help people adequately prepare for the tasks required. For example, provide questions, meeting agendas or documents ideally one to two weeks in advance to allow time to review and consider responses
- Provide opportunities for people to share their thoughts after interactions and group discussions. For example, offer debriefing sessions and check in with them the day after the interaction.
- Be open to varied platforms for communication that are familiar and easy to navigate for each individual. Many people use their mobile devices with their preferred assistive technology software and accessibility settings for information access.

4. Provide clear and regular updates

Providing regular updates and feedback will enhance the involvement process.

How to do this:

- Clearly communicate what can and cannot be achieved through their collaboration. Explain the constraints (e.g. legal, ethical, financial, timeline) and any limitations in resources and decision-making power.
- Provide regular feedback on how the project is tracking, regardless of whether there is any progress. Include where and how their lived experience input has been incorporated.

- Consider broader reach in your communications e.g. CERA website, Cerulea website, Visionary magazine, Eye News and other newsletters.

5. Acknowledge contributions

It's essential to recognise and value the time and effort lived experience collaborators provide throughout the research process.

This may be supported by:

- Remuneration as either a gift card or hourly rate (see Chapter 4 for further guidance)
- A thank you card
- Opportunities to have conference registration paid
- Travel reimbursements
- Openly acknowledging their contribution in team meetings
- Certificate of appreciation
- Paying for them to attend and co-present at a conference
- Having lived experience collaborators as authors on papers and/or recognised as co-investigators on grants.

For research with long term outcomes, it may be relevant to communicate that their contributions now may not be translated until much later i.e. it could help future generations.

What is information accessibility and why is it important?

Australian law mandates that everyone has an equal right to information. Inclusive participation and access to information for all people, no matter their abilities or circumstances, is the responsibility of all organisations.

Information accessibility is the targeted actions that are undertaken to promote **information access.** Information access is the ability to find information, engage, consume or use it, and to understand it. (See glossary for a more detailed explanation of these terms.)

Information accessibility includes:

- **Accessible language:** This means using plain language, and avoiding medical jargon and too many acronyms.
- **Accessible format**: This means providing print information in a format that the recipient chooses is best for them e.g., digital Word, large print.

The VisAbility guide in the appendices provides a checklist for creating an accessible Word document.

Universal Design principles

Universal Design principles focus on designing environments, products and systems for the widest possible range of users from the outset. This is in contrast to the approach of adapting or retrofitting for specific needs later.

In the context of collaborating with people who have lived experience, we need to think about accessibility at the planning stages of a research project. Universal design principles should also be considered across the research life cycle to ensure that research outcomes can be meaningful to a wider audience.

Accessibility considerations for partnering with lived experience collaborators

A person's visual ability and capability can vary depending on the situation and the tools offered to enable information access. It can also be impacted by factors like light levels, time of day and the physical and emotional wellbeing of the person.

Each person will have a different experience of their visual capability and ability. The translation from seeing letters on a vision chart to how a person functions in their daily life is not directly comparable. Asking a person to describe what they can do with their vision, or what they can see, is encouraged. This is opposed to asking someone to describe what they can't see, which is a more 'ableist' view. Care should be taken to ensure that the focus is on what is possible, rather than what is not possible. It's also important to respond sensitively if someone is feeling discouraged about not being able to complete a task.

People shouldn't need to 'declare' every issue they may have in order to assess accessibility requirements. However, when partnering with lived experience collaborators, researchers should adopt a considered and respectful approach. Being proactive is key. Offer collaborators the choice and control over what accessibility options are most helpful given the level of interaction required.

Tips for researchers

Recognise individual complexity

- Understand that each person's experience is unique and shaped by multiple intersecting factors.

- Avoid making assumptions based on a single aspect of a person's identity.
- Be aware of your assumptions and biases based on what you think someone can or can't do.

Practise cultural humility

- Acknowledge your own biases and limitations in understanding diverse experiences.
- Be open to learning from participants about their lived experiences.

Use inclusive language and practices

- Employ person-first or identity-first language as preferred by the individual.
- Ensure all tasks, activities and processes are accessible and adaptable.
- Ask the participant if they would like an explanation about how something works or why particular processes are in place e.g. what a piece of medical equipment does or why we ask them to respond in a certain way.

Adopt flexible involvement methods

- Ask people directly what actions can be taken to ensure they can participate fully in the activity.
- Organise meetings and activities that can accommodate various communication and participation styles.
- Be prepared to modify your approach based on individual needs and preferences.

Address power dynamics

- Be aware of the power imbalance between researchers and lived experience collaborators.
- Create opportunities for collaborators to have agency in the task or activity.

Provide comprehensive support

- Offer multiple forms of assistance e.g. communication aids, breaks, support persons to attend meetings alongside the collaborator as needed.
- Be prepared to address various accessibility needs simultaneously.

Respect privacy and boundaries

- Be sensitive to the potential vulnerability of lived experience collaborators.
- Allow individuals to determine what information they're comfortable sharing.

Learn from experts

- Consult with others in the organisation who have more experience with engagement principles.
- Review information and resources produced by leading disability support organisations.

Offer accessible communication

- Present communication and information in multiple formats and optimal font size to ensure accessibility (see resources in further reading).
- Offer choice and control to people around accessibility options.

Commit to ongoing learning

- Stay informed about the evolving understanding of disability.
- Be open to feedback and willing to adapt your approach over time.

Other factors that can impact participation

Our performance on any given day can be impacted by a range of factors, like tiredness, hunger, health conditions or our emotional state.

There may be several impacts experienced at the same time. For example:

- Fatigue
- Difficulty with mobility affecting hands for computer use
- Brain fog
- Delayed response from impacts with speech expression
- Slow typing.

Being mindful that multiple impacts can affect capacity is critical to supporting people to participate in a way that suits their needs.

> **Always ask the question: "How can we support you to participate fully in this activity?".**

There may also be mental health consequences from sharing lived experience stories. For some, the recounting of their story may trigger emotions, such as grief. In these situations, acknowledging the impact is important (refer to unintentional harm or distress, page 17).

Reflective questions

- Do you routinely simplify your emails to ensure they are short and concise? Remember accessibility is for everyone, both inside and outside the centre.
- Can you summarise your research into two to three sentences?
- Would an in-person or online meeting be most accessible? See the resources by Disability Gateway and Round Table listed in further reading.

Further reading

Accessibility resources

- Round Table's **guidelines for producing accessible formats** including audio, braille, large print, e-text and tactile graphics.
- Australia's Disability Strategy Hub, **Good Practice Guidelines for Engaging with People with Disability**.
- Disability Gateway's **Guidelines for Creating Accessible Materials,** including audio, video, forms, surveys, presentations, images and diagrams, print and digital documents.
- **Centre for Accessibility Australia** provides resources and education opportunities on all aspects of accessibility including document accessibility.

Health literacy resources

- **Sydney Health Literacy Lab** has developed an online health literacy editor which gives you real-time feedback and readability scores.
- **Australian Clinical Trials Alliance** provides guidance around communicating in plain language.

Culturally safe resources

- **Collaborate & Connect:** A toolbox for non-Indigenous organisations to better engage with First Nations young people.
- **Steps for involving Aboriginal and Torres Strait Islander Communities**, prepared by Aunty Kerrie Doyle on behalf of the Australian Health Research Alliance.

Key papers

- **Psychological Impact of Vision Loss** (Boagey et al., 2022).
- **Dismantling barriers to research and clinical care for individuals with a vision impairment** (Robertson et al., 2025).

Chapter 4: The CERA group's Partnership Standard

This chapter looks at consumer involvement from a best practice and research governance point of view, and how this has informed our Partnership Standard.

It explains:

- The industry standards and national policies on involving lived experience collaborators in healthcare research
- Grant schemes requiring consumer involvement
- CERA's Partnership Standard and the five stages of implementation
- Remuneration recommendations for lived experience collaborators

Industry standards

There are two national frameworks that govern consumer involvement in health and medical research in Australia:

- National Statement on Consumer and Community Involvement in Health and Medical Research: Outlines the requirements for researchers to effectively involve consumers across the research life cycle.
- National Safety and Quality Health Service (NSQHS) Standards: The 'Partnering with Consumers Standard' has informed our own Partnership Standard.

Both frameworks are currently being reviewed and will be updated in 2025/26.

The Consumers Health Forum (CHF) of Australia is the national peak body working with the sector to promote uptake of these standards in practice.

Grant schemes requiring consumer involvement

An increasing number of grant funding schemes require consumer involvement. On average, 120 grant applications are made with CERA as the administering organisation each year. Of these, around 30 are successful (25 per cent).

Several competitive grant schemes already require consumer involvement. This includes the MRFF, NHMRC, and Macular Disease Foundation of Australia. The number of funders expecting embedded consumer involvement is expected to grow.

Our Partnership Standard

Involving people with lived experience of vision loss and its impacts is central to CERA's organisational strategy '[Impact through Innovation 2025–2030']**.** Engagement with lived experience experts as consumer representatives is central to the strategy's **Partnering for impact** objective. CERA has set a target of 50 per cent of CERA research involving lived experience collaborators by 2030.

Our Partnership Standard aims to create research programs that look after the needs and priorities of our lived experience collaborators. It focuses on four key areas: organisational leadership, building capacity, using a best practice framework, and accessibility (see **Figure 3)**.

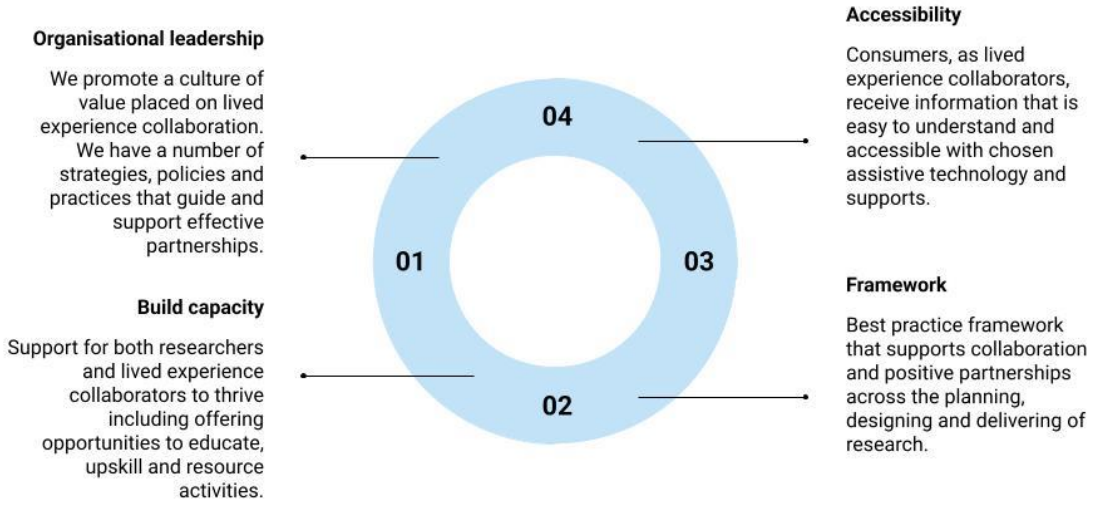


Figure 3: The CERA group's Partnership Standard

How we embedded our Partnership Standard

Leadership buy-in, a supportive culture, and resourcing commitments have been key to putting our Partnership Standard into practice.

Table 3 outlines our staged implementation approach, which was informed by the West Australian Health Translation Network Handbook.

Table 3: Steps for adopting the Partnership Standard

Stage	Actions
1. Commitment	• Best Practice Guide • Education module • Staff information forums
2. Planning and preparation	• Checklist for collaborators • Checklist for researchers • Welcome letter for collaborators
3. Orientation	• Information sessions • Communication in Eye News, Visionary magazine and CERA and Cerulea websites • Project team meetings organised by Lead Researchers • Lived experience collaborator position description
4. Monitoring and evaluation	• Periodic 'spot checks' undertaken by the Consumer Involvement and Advocacy Lead with each lived experience collaborator • Consultations undertaken by the Consumer Involvement and Advocacy Lead and each researcher at periodic intervals across their project
5. Concluding involvement	• Acknowledgement of time and value • Communications plan in place to ensure that results from the research are offered to the community • Lived experience collaborators helping to disseminate the research findings in plain language

Remuneration requirements

Our Partnership Standard involves acknowledging the value that our lived experience collaborators have in our research. Refer back to page 24 for different ideas on how to acknowledge their contribution.

The CERA group requires that researchers factor payments to lived experience collaborators into their project budgets and grant applications.

Lived experience collaborators bring invaluable insights from their personal experience of vision impacts, rehabilitation, treatments and the eyecare system. It is essential to recognise that this insight cannot be accessed through traditional research methods. It can only be gained by directly engaging with lived experience collaborators in delivering research together.

Paying lived experience collaborators acknowledges that their contributions are as valuable as those of clinicians or researchers. It moves beyond tokenistic involvement to genuine collaboration. It also ensures that participation isn't limited to those who can afford to volunteer. This approach diversifies perspectives, ensuring ethical research that respects each individual's unique needs, including collaborator-researcher interactions, and ultimately reflecting a wider range of real-world experiences.

Paying lived experience collaborators is supported by:

- Funding bodies like the NHMRC
- Industry leaders such as Australian Clinical Trials Alliance (ACTA) and Australia's Health Translation Network consumer program
- Leading research groups like the VCCC alliance, Monash Partners and Melbourne Social Equity Institute.

In line with industry standards, CERA requires the following reimbursements (in AUD):

- $50 per hour for co-design and collaboration activities,
- $70 per hour for co-led projects or where the consumer partner has a more strategic advisory role in the project team,
- $150 per hour for panel engagements.

Reflective questions

- Have you contacted the Consumer Involvement and Advocacy Lead to discuss the role of lived experience collaborators in your project?
- Have you read the lived experience collaborator and researcher checklists?
- Have you listed 'consumer involvement' in your Intention to Submit New Project form?

- Do you have questions about, or need training on, how the Partnership Standards are used?

Further reading

From CERA

- **Impact through Innovation Strategy 2025–2030.**

From Government bodies

- **Draft Statement on Consumer and Community Involvement in Health and Medical Research** (2025).
- **Consumer Fact Sheet 3: Partnering with Consumers Standard** (2018).
- **Writing in plain language guide** for summaries of published research that can be created with lived experience collaborators.

Glossary of terms related to consumer involvement

Ableism: Discrimination that favours 'able-bodied' people or people without disability. Examples include physical barriers, inaccessible information, using deficit-focused language (as opposed to strengths-based language).

Australian Charter of Healthcare Rights: Specifies the key rights of consumers when seeking or receiving healthcare services. It was endorsed by health ministers in 2008, with a second edition released in 2019.

Blindness: There is no consistent definition of blindness. In our local context, blindness refers to total vision loss (no light perception). See also legal blindness and low vision.

Brain fog: Not a medical condition, but rather a term used to describe a set of symptoms. It refers to a state of mental confusion, lack of focus, and reduced cognitive function. It can affect a person's ability to think clearly, remember things and concentrate effectively.

CALD (culturally and linguistically diverse): CALD is a broad name for communities not of Anglo-Saxon origin and includes people from any number of diverse ethnic backgrounds.

Carer: A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail or aged.

Clinical governance: An integrated component of corporate governance of health service organisations. It ensures that everyone – from frontline clinicians to managers and members of governing bodies, such as boards – is accountable to patients and the community for assuring the delivery of safe, effective and high-quality services.

Communication order: A speaker order to ensure that everyone gets a chance to speak. People have the option to speak or pass their turn. It is facilitated by the meeting host.

Community-Based Participatory Research: A collaborative approach to research that equitably involves community members, organisational representatives and researchers.

Consumer: In our context, it is a person who has lived experience of an eye condition or vision impairment, or a parent, carer or trusted support to a person with vision impairment.

Consumer involvement: Consumers and community working in partnership with health professionals and researchers to shape what research or project is being done, how it is carried out and how results are shared and applied in practice.

Consumer representative or advocate: A person who offers a consumer perspective and consumer experiences, and who advocates and takes part in decision-making processes in the interests of people who participate in clinical research.

Cultural safety: Fostering an environment where individuals from CALD backgrounds, marginalised or underrepresented communities feel respected, valued and free to express their cultural identity without fear of discrimination, judgment or exclusion.

Health literacy (environment): The infrastructure, policies, processes, materials, people and relationships that make up the health system, which affect the ways in which consumers find and use health-related information.

Health literacy (individual): The skills, knowledge, motivation and capacity of a consumer to access, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action.

Information access: The ability of a person to find information, engage or use it, and to understand it. The definition extends to all methods of communication. Information access can be promoted through accessible information.

Information accessibility: The targeted actions that are undertaken to promote information access. Providing information in an accessible way means providing the appropriate resources to enable a person autonomy and independence in their engagement with the information provided. It includes providing options so people can access the information to suit their needs and communicate their response in a way they choose. Equitable access to information means providing the environment and opportunity for a person to participate in decisions affecting them, communicate their will and preference and develop their own decision-making ability.

Legal blindness: In Australia, legal blindness is defined as either reduced distance visual acuity or a visual field restriction (distance visual acuity impairment of 6/60 [20/200] or less in the better eye, or a binocular visual field restriction to the central 10 degrees, or both).

Lived experience: The perspectives of someone who has an eye condition, or cause for vision impairment encompassing low vision and blindness. The implicit knowledge and understanding of the impact of vision impairment on everyday life represents unique expertise and firsthand experience. The 'lived experience' term extends to those who support people who have a chronic eye condition such as a parent, carer or trusted support person.

Lived experience collaborator: A term selected by our current Consumer Advisory Group to reflect the role that people with lived experience have in our research context. Lived experience collaborators are partners in the research conduct, and provide insights and ideas across the research journey.

Low vision: In Australia, low vision generally refers to very reduced vision in the legal blindness spectrum. The definition applied by the CERA group is visual acuity with best possible correction between 6/18 and 3/60. Functionally, a person may not be able to read, recognise faces or drive. Ultra-low vision is considered to be less than 3/60 and includes perceiving large form vision and light perception.

Partnering: When people with lived experience work together in a collaborative relationship with researchers, staff and students at the CERA group. This relationship is supported by the CERA group's Partnership Standard.

Patient: In our context, this represents a clinical research participant who may be receiving an experimental treatment or therapy for their eye condition.

Person-centred research: Research that places the consumer, patient or participant voice at the core, ensuring their preferences, needs and values drive the research purpose and objectives.

Partnership Standard: A best practice framework that aims to create a safe, respectful and inclusive environment that encourages the meaningful and sustainable participation of people with lived experience as equal partners in the research. See Chapter 4 for further detail on our Partnership Standard.

Plain Language Summary: sometimes called a *lay summary* – explains the importance of scholarly or scientific research in clear, accessible terms. Its purpose is to make complex evidence understandable to a wide range of audiences by avoiding technical jargon. These audiences may include practitioners, policymakers, professionals in related fields, and members of the general public. Lived experience collaborators should be equal partners in developing these summaries.

Research: the collective term used in this document to describe all stages of research including the planning, undertaking and evaluation of research e.g., preparatory stages, data collection and analysis, implementation of outcomes, research results dissemination.

Researchers: the professionals that partner with lived experience collaborators at the CERA group e.g., scientists, study coordinators, investigators, students, research support staff.

Shared decision making: A process whereby lived experience collaborators are involved in planning and decisions about 'what, why, when and how' the research will be done to better reflect the perspectives of the intended population.

Unconscious bias: The automatic, unintentional judgments we make about others, often shaped by our upbringing, cultural environment, and even ingrained in memory patterns from our ancestors, through DNA memory. These biases can result in unfair treatment based on characteristics such as race, gender, health, appearance, or age.

Appendices

Appendix 1: VisAbility accessibility checklist

This accessible checklist below and online outlines key elements that should be considered when creating accessible documents.

Document properties

Add Title, Author and Keywords (tags) in the Properties Panel.

Easy to navigate

Headings

- ☐ Headings are formatted using pre-set styles.
- ☐ Headings are logically ordered in a hierarchical fashion.

Hyperlinks

- ☐ Hyperlinks and email links are active/live.
- ☐ Link text is descriptive, don't just list the URL. e.g. VisAbility website.

Page numbers

- ☐ Page numbers are included in documents with more than one page.

Tables

- ☐ Tables are solely used to represent data.
- ☐ Tables have a bold, visible border and there is adequate space between the border and contents of a cell.
- ☐ Header rows are specified in tables.
- ☐ Header rows are repeated on each page the table runs across.

Table of contents

- ☐ Large documents have a table of contents.

Clear visual style

Font

- ☐ Text size is a minimum of 14 point and headings a minimum of 16 or 18.

- ☐ Bold is used to emphasise text rather than italics and underline.

Images

- ☐ Images have a description or 'alt text'. Alt text descriptions are included in the **description field**, not in the **title field** in the MS Word dialogue box.
- ☐ Images are set as 'inline' with the text.

Layout

- ☐ Layout is consistent, logical and in a linear order.
- ☐ Minimum 1.2 line spacing, 12pt space between paragraphs.

Text

- ☐ Text has a clear typeface (San Serif font family).
- ☐ Text is legible and not placed over background images.
- ☐ Text is left-aligned and set horizontally.

Colour and contrast

- ☐ High colour contrast between text and background.
- ☐ Uniform text colour for easier colour contrast conversion as needed.
- ☐ Information is not solely conveyed through colour.
- ☐ Use the **TPGi Colour Contrast Analyser** to check colour contrast meets accessibility requirements.

Other considerations

- ☐ Use simple language: short sentences and words.
- ☐ Sentences with a limit of 12 words.

Accessibility Checker

- ☐ Document is checked for accessibility using the Accessibility Checker in Word.

Word to PDF

- ☐ Tick the 'Document structure tags for accessibility' and 'Create bookmarks' when exporting to PDF.

Appendix 2: Key websites on consumer involvement in Australia

Australian Commission on Safety and Quality in Health Care

This website provides detailed information on the NSQHS Standards, accreditation and the Australian Charter of Healthcare Rights. It includes fact sheets, user guides, posters and other resources.

Consumers Health Forum of Australia (CHF)

CHF is the national peak body for consumers in Australia. It offers information on national policy and issues important to health consumers.

State and territory health consumer peak organisations

These organisations have a network of consumers who can work with health service organisations. Most offer training for consumers who would like to be advocates, and have lots of helpful resources and programs.

- Health Care Consumers' Association (Australian Capital Territory)
- Health Consumers NSW
- Health Consumers Queensland
- Health Consumers Tasmania
- Health Consumers Centre (Victoria)
- Health Consumers' Council (Western Australia)