

Leukaemia Foundation Lived Experience Engagement Program (LEEP) Handbook

Welcome to Your Lived Experience Journey

Thank you for taking this key step in your health journey. Whether you are looking to give back, find meaning from you or your loved one's health journey, improve experiences for future patients, or make your voice heard in blood cancer care, we are excited to have you join our Lived Experience Engagement Program.

This handbook is your one-stop guide to understanding lived experience engagement, finding your place in the program, and making the most of your experience with us. We hope you find satisfaction and personal fulfillment as you help shape the future of blood cancer support and services.



Table of Contents

Getting Started

- About the Leukaemia Foundation
- Understanding Lived Experience Engagement
- Our Principles for Meaningful Engagement

Getting Involved

- How to Join
- What to Expect and How to Stay Involved
- Our Commitment to You
- Your Commitment

Finding Your Level

- Three Levels of Engagement
- Level 1 – 3 Activity Opportunities
- Your Pathway to Involvement

Building Your Skills

- Level 2 Skill Development
- Level 3 Advanced Training

Support and Recognition

- Our Support for You
- Recognition and Appreciation

Activity Completion and Follow-up

- What Happens After Each Activity
- Measuring Impact Together

Resources

- Frequently Asked Questions
- Helpful Resources
- Contact Information

Getting Started

About the Leukaemia Foundation

Before diving into how you can participate in the Lived Experience Engagement Program, it is important to understand who we are, what we stand for, and the impact we are working to achieve together.

Our Story

 [History of the Leukaemia Foundation](#)

 [Understanding Blood Cancer](#)

Our Key Campaigns

- **National Action Plan:** [Learn more](#)
- **Set the Standard:** [Blood cancer treatment standards](#)
- **World's Greatest Shave:** [Our flagship fundraising event](#)

Our Commitment to Quality

We have achieved voluntary accreditation against the National Safety and Quality Primary and Community Healthcare Standards. This accreditation demonstrates our commitment to safety, quality, and continuous improvement—and our dedication to setting benchmarks for excellence in caring for the blood cancer community, especially those most vulnerable. [Learn about our quality commitment.](#)

Key Terms for this handbook

Lived Experience Partner: Individuals registered in our LEEP - people living with and beyond blood cancer, including patients, carers, and loved ones with lived experience

Expression of Interest (EOI): When you put your hand up for an advertised activity

Understanding Lived Experience Engagement

What is a Lived Experience Engagement Program?

Our lived experience engagement program ensures people with lived experience of blood cancer meaningfully shape our services, research, and advocacy affecting their community.

The program is open to people who have had blood cancer, who are living with chronic blood cancer, their caregivers, and bereaved loved ones. We call these individuals Lived Experience Partners. The program offers individuals with lived experience (you) to be engaged and involved at the level that matches your interests, availability, and skills.

This engagement includes everything from educating people about our work to inviting them to share their blood cancer experiences. We also consult with them on specific issues and involve them in decisions that directly shape our programs and services.

In consultation with people with lived experience, three flexible levels of engagement that have allocated activities were determined, and these include:

- **Level 1: Light Engagement**
- **Level 2: Moderate Engagement**
- **Level 3: High-Level Engagement**

These levels offer every person registered in the program an opportunity to contribute and ensure their voice is heard. Please see page 12 for more information about the levels of engagement.

Why Your Voice Matters

Your lived experience provides insights that can raise awareness of blood cancer, participate in decision-making, and improve services for the entire blood cancer community. Whether it is spotting confusing language in a patient brochure, sharing what support you wished you had, or suggesting practical improvements to our services, your perspective helps us get it right.

By engaging people living with blood cancer, we:

- **Elevate authentic voices** in raising awareness and the decision-making processes
- **Follow best practices** aligned with Australian healthcare standards and Australian Cancer Plan priorities
- **Fulfill our patient-first commitment** across all our work
- **Drive better outcomes** for people living with blood cancer, health professionals, and our community.

Lived Experience Spotlight: *"Through my involvement in the LEEP, I've been able to turn my difficult journey into something meaningful that helps others. It's given me purpose and connection during a challenging time."* - Glenys, LEEP Member

Our Commitment to All Voices

Every voice matters. Every story has value. Every individual deserves respect and inclusion. We believe that diverse perspectives strengthen our work and lead to better outcomes for the entire blood cancer community.

Our Understanding of Diversity

Our Approach to diversity includes embracing differences in:

- Cultural background and ethnicity
- Aboriginal and Torres Strait Islander heritage
- Language, communication, and literacy
- Age and life stage
- Gender identity and sexual orientation
- Religious and spiritual beliefs
- Physical and cognitive abilities
- Socioeconomic status
- Geographic location (including regional/remote)
- Lived experience of illness, disability, or caregiving

Our Principles for Meaningful Engagement

The program has established six core principles to ensure we facilitate meaningful engagement. These principles were determined in consultation with some of the lived experience individuals in the program.

Authentic Partnership

- We work with blood cancer individuals with lived experience as equal partners, recognising their knowledge from experience, research, and shared stories.
- We value everyone's contributions and ensure people with lived experience help shape our work.

- We involve individuals with blood cancer lived experience in developing programs, policies, and resources.
- Blood cancer individuals with lived experience are essential for raising awareness and helping make decisions about services, advocacy, and community education.
- We build trust through welcoming, respectful, and understanding engagement practices.

Person-Centered Approach

- We adjust our approach to suit each person's situation, preferences, and capacity.
- You choose which activities to join and your level of involvement—it's always your decision.
- We use respectful, people-first language in all our communications.
- We understand that blood cancer affects carers, families, and people of all ages differently.
- We know blood cancer impacts everyone differently, so we're careful and supportive when discussing difficult topics.

Accessible, Inclusive and Culturally Responsive

- We make our engagement fair, inclusive, and responsive to the diversity of people impacted by blood cancer.
- We remove barriers to participation, particularly for those in rural and regional areas, people with disabilities, and people from different cultural and language backgrounds.
- Engagement opportunities are accessible and culturally appropriate for everyone, regardless of where they live, what language they speak, their access to technology, or their personal situation.
- We use inclusive language and actively consider the needs of people living with disabilities.

Mutual Capacity Building

- We recognise that learning and growth occur in both directions—between individuals with lived experience and staff—strengthening the whole blood cancer community.
- Both individuals and staff are expected to develop skills and build unique capabilities for effective engagement.

- Knowledge sharing, peer learning, and community wisdom enrich our work.
- We create environments where individuals with lived experience feel safe to contribute, knowing their insights are valued.

Open, Informative and Accountable

- We commit to being open and honest in all lived experience engagements.
- We clearly explain how people can get involved and what their role involves.
- We communicate in plain language and make information easy to understand.
- We are open about how your contributions are used and "close the loop" by showing what changed because of your input.
- We will tell you about any risks or consequences of participation, including privacy considerations and if your involvement might be public.

Commitment to Continuous Improvement

- We focus on future needs and use lived experiences to improve service delivery.
- We remain open to improving our engagement methods based on what works best for our community.
- We respond to changing lived experience individual needs with continuous improvement driven by evidence and feedback.
- We evolve based on what works best for our community's changing support and care needs.

Getting Involved

How to Join the Program

Step 1: Registration

If you are reading this as a new Lived Experience Partner, you have already completed this step - welcome!

Complete our online registration form where you will tell us about:

- Your blood cancer experience
- Your interests and availability
- The levels of engagement you are interested in
- Any support needs

Step 2: Getting to Know You Call

After you have registered for the program, you can join one of our regular induction video calls to:

- Meet other new lived experience members
- Share more about your journey
- Ask questions about the program
- Understand what is available

Step 3: Engage at Your Level

We will use the activity preferences you indicated during registration to match you with suitable opportunities.

You can always:

- Begin with Level 1 activities
- Explore Level 2 opportunities
- Consider Level 3 for higher level engagement

What to Expect and How to Stay Involved

To support you to stay engaged and aware of engagement opportunities, we provide regular communication in the following ways.

Monthly SMS Updates

- Quick reminder to check our lived experience e-noticeboard for new opportunities. Click [here](#) to view current openings.

4-monthly Newsletter

- Updates about the program and stories from fellow lived experience members- [View a recent edition](#)

WhatsApp Community Group

- WhatsApp is a free messaging app you can download on your phone or use on your computer. It lets us share quick updates with our lived experience community through a group chat format.
- Get weekly updates about emerging opportunities  Join our WhatsApp Group by clicking [here](#).

- *Privacy note: We will not share your phone number, and you do not need to provide your last name.*

Monthly Engagement Zoom Calls

For those wanting more engagement:

- Learn about new activities
- Hear from guest speakers
- Connect with other lived experience partners

Updating Your Profile

Life changes, and so might your interests or availability. As an active member of our Lived Experience Engagement Program, we will continue to match you with suitable opportunities, but there is no pressure to participate in every activity - you remain in control.

As your circumstances change, you can always update your activity preferences, take breaks from participation, or move between various levels of engagement by contacting your coordinator.

Our Commitment to You

Understanding Your Rights

As a lived experience partner, it is important to know your fundamental rights in healthcare settings and lived experience engagement activities.

Charter of Healthcare Rights

At the Foundation, we adhere the Australian Charter of Healthcare rights.

For a quick overview of your fundamental healthcare rights (2-minute read), [click here](#)

Insurance and Safety

- Public liability insurance coverage during face-to-face activities
- Safe, respectful environment for all participants

Financial Support

- Reimbursement for approved expenses (more details below)
- Accommodation for interstate participants (pre-approved)

Fair Treatment

- Consistent, transparent matching of individuals with lived experience to activities
- No favoritism - matching based on profile and activity requirements
- Respect for your time and expertise

Privacy Protection

- Secure, encrypted lived experience database
- Limited sharing of your personal situation with relevant staff only
- Your consent is required before sharing details with external organisations
- Secure platforms for all communications

Your Commitment

Professional Conduct

- Treat all staff, lived experience partners, and stakeholders with respect
- Engage constructively, even when opinions differ
- Honor time commitments and provide advance notice if unable to participate

Confidentiality

- Uphold confidentiality agreements (where applicable for Level 3 activities)
- Only share information you have permission to share
- Respect the privacy of other participants

Constructive Participation

- Provide feedback in a respectful, solutions-focused manner
- Declare any conflicts of interest
- Promote inclusion and respect diverse perspectives

Finding Your Level

Three Levels of Engagement

Our three-level approach recognises that everyone's journey with lived experience engagement is different.

Whether you are testing the waters, ready to share your story more broadly, or wanting deeper involvement in our work, we have designed pathways that meet you where you are.

These levels are not a ladder you must climb - they are flexible options that adapt to your comfort, availability, and interests as they evolve.

You can choose the level that works for you and move between levels in any direction based on what works for you at any given time.

Level 1: Light Engagement

Level 1 activities are primarily online and self-directed.

Perfect for: First-time participants or those with limited time availability

Time Commitment (per activity): Usually, 30 minutes or less

What's Required:

- Join a "Getting to Know You" video call
- Read required sections of this handbook (pages 14-18)
- Engage in activities as they arise

Level 2: Moderate Engagement

Level 2 introduces more interactive formats like interviews, podcast recordings, and group discussions which may be face to face or online or over the phone.

Perfect for: Those ready to share their story and engage more actively

Time Commitment (per activity): 45 minutes to several hours, usually one-off activities

What's Required:

- Join a "Getting to Know You" video call
- Read required sections of this handbook (pages 3, 14-18)
- Participate in a brief readiness check-in with our team to confirm your emotional readiness for the activity
- Optional storytelling and media training available

Level 3: High-Level Engagement

Level 3 moves into collaborative spaces with committees, facilitation roles, and active participation roles.

Perfect for: Those ready for ongoing commitment and collaborative roles

- **Time Commitment (per activity):** One hour or more per session, with regular sessions over a typical program duration of 1-2 years

Version 2.0	Published 08.26	Review 08. 2027
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What's Required:

- Join a "Getting to Know You" video call
- Read required sections of this handbook (pages 3, 14-18)
- Participate in a more comprehensive readiness and suitability conversation (approximately 20 minutes) prior to commencement to assess your experience, emotional readiness, capacity, and understanding of what participation involves
- Complete mandatory induction training (required for specific activities like peer support and committee roles)
- Sign confidentiality and terms of reference documents



Remember: You can move between levels as your confidence, availability, and interests change. Our approach is interactive - you choose your involvement

Flexibility is Key

Level 1 – 3 Activity Opportunities

Here are some more detailed examples of the activities available at each level. This is not an exhaustive list - new opportunities arise regularly based on our work and community needs (see below in 'Impact and Influence' section)

As you progress through the levels, you will notice several key changes:

Training and Support:

Level 1 requires minimal preparation - we provide what you need to participate effectively. Level 2 offers optional training to help you feel confident in media or public-facing roles. Level 3 includes mandatory training tailored to specific roles, ensuring you have the skills and knowledge needed for leadership positions.

Impact and Influence:

Your voice matters at every level, but the scope of influence grows - from improving individual services (Level 1) to shaping public awareness (Level 2) to contributing to decision-making that informs our programs and services (Level 3).

The following table provides detailed examples of activities you can participate in at each level.

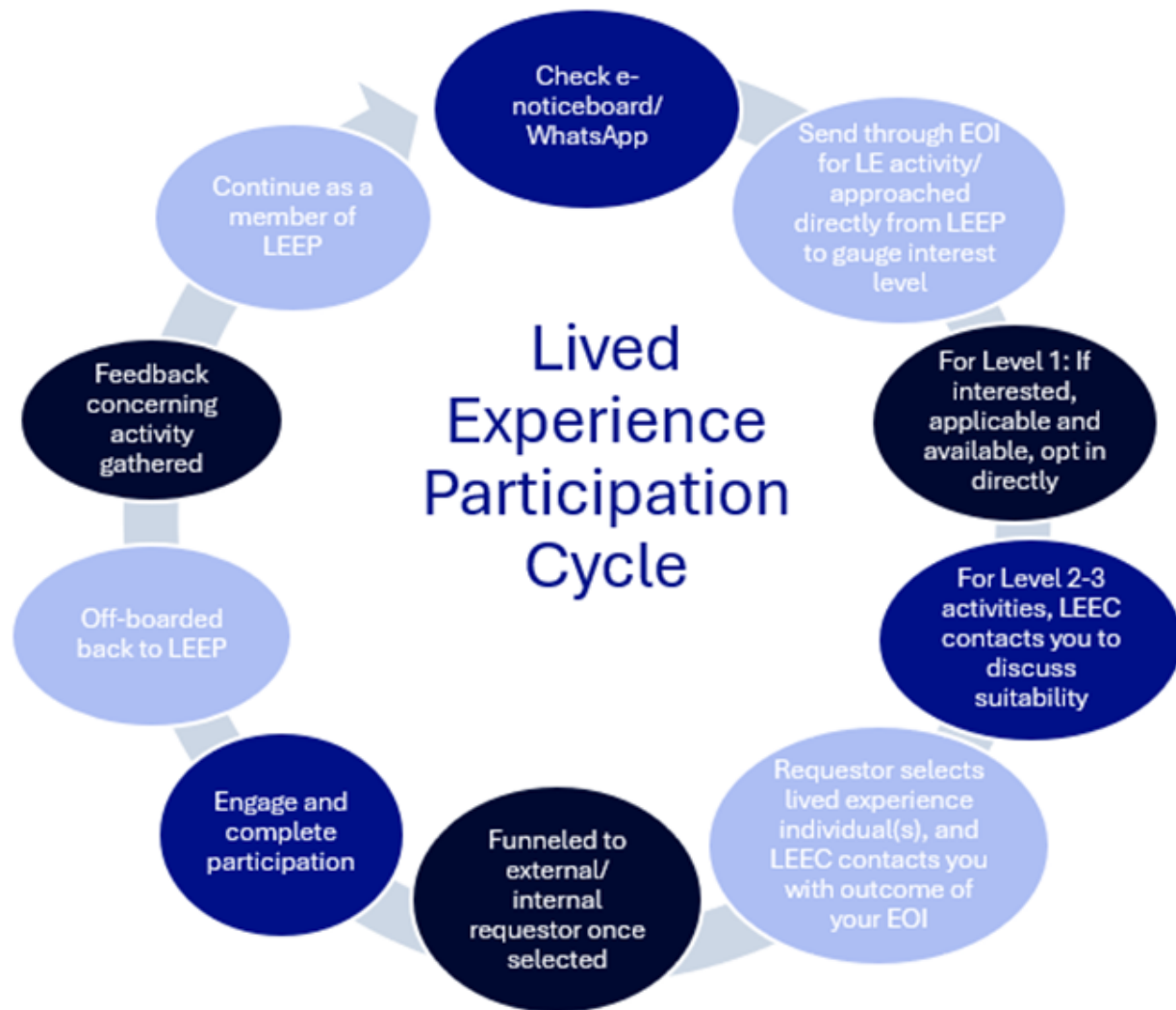
Version 2.0	Published 08.26	Review 08. 2027
-------------	-----------------	-----------------

Level	Type of Activity	Time Commitment (per activity)	Training and Support	Format
Level 1	External Research Surveys	10–20 minutes	None	Online surveys and questionnaires
	Staff Surveys	10–20 minutes	None	Online surveys and questionnaires
	Program Feedback	15–30 minutes	None	Online feedback forms or brief phone conversations
	Staff Project/Activity Feedback	20–30 minutes	Project-specific guidance	Online reviews, feedback forms, or brief video calls
Level 2	Media Engagement	1–3 hours	Optional media training	Interviews, written stories, video content
	Social Media Campaigns	30 min – 1 hour	Guidelines and content provided	Scheduled posts, story sharing, hashtag campaigns
	Donor Appeal Campaigns	2–4 hours	Campaign-specific storytelling support	Written content, video testimonials, or campaign events
	Focus Groups & Consultation Panels	1–2 hours	Session guide and overview	In-person or online group discussions
	Podcasts	1–2 hours (incl. prep)	Pre-recording guidance	Audio recording, typically conversational interview style
	Spokesperson Roles	Varies	Key message briefing and speaker training	Public speaking, event representation, or

				media appearances
	Health Literacy Reviews	1-2 hours	None	Online review and feedback
Level 3	Service Improvement Committees	Ongoing (med-long term)	Committee participation training	Regular committee meetings and consultation sessions
	Research Program Participation	1-2 years	Research literacy and ethics training	Committee meetings, review sessions, grant application reviews
	Peer Support Programs	Flexible	Full training + ongoing supervision	Phone, video, or in-person support sessions
	Lived Experience Advisory Group	Periodically throughout year	Committee participation training	Regular group meetings (online or in-person)

Your Pathway to Involvement

The Lived Experience Engagement Cycle diagram shows the different levels available to you. You can enter at any level and move between levels in any direction based on what works for you. The process is designed to be supportive and flexible, meeting you where you are in your journey.



How the Process Works

For All Levels: You will start by registering and joining a "Getting to Know You" call to understand the program and share your interests.

How You Will Be Matched to Activities: Most opportunities are advertised to the broader LEEP community, and you can express interest in any activities that are relevant to you. Occasionally, we may reach out directly to individuals when an opportunity requires specific perspectives, experiences, or participant characteristics. Any direct invitations are guided by the information provided in your registration profile and are intended to help ensure the right mix of voices is represented.

Level 1 Activities: When opportunities are advertised, you can participate by clicking a link or emailing your coordinator to express interest. These activities are designed to be accessible without additional screening.

Level 2 Activities: An engagement activity will be shared on the lived experience engagement online page or sent by the WhatsApp group chat. After submitting an Expression of Interest (EOI), we may contact you to discuss the opportunity further and explore whether it is a good fit. Before committing, it's important to reflect on your own readiness and emotional capacity for the opportunity.

Level 2 activities may involve sharing personal experiences in more visible settings and can have a greater emotional impact. Examples include sharing your patient testimony, engaging with media outlets, or recording a podcast. These activities ask you to share vulnerable aspects of your experience publicly or with professionals, which takes emotional energy. Our brief readiness check-in (typically a few minutes) focuses on confirming your emotional readiness and understanding your capacity for the activity. This conversation also gives you a chance to ask questions and fully understand what's involved before committing.

Level 3 Activities: These are our highest-level engagement opportunities and require a more formal suitability assessment. When you express interest in a Level 3 activity, a member of the lived experience engagement team will schedule a readiness and suitability conversation with you before you begin prior to the selection process. This comprehensive conversation (approximately 20 minutes) assesses your experience, emotional readiness, capacity, and ensures you have a full understanding of what participation involves.

This pathway is not linear - you might participate in Level 1 activities while engaging in Level 2 opportunities or move between levels as your interests and circumstances change.

Building Your Skills

Level 2 Skill Development

These supplementary resources support your growth as a confident lived experience partner, especially if you are moving toward committee participation or advocacy roles.

Partnering with Lived Experience Partners Guide

[Download guide \(48 pages\)](#) *Comprehensive guide on effective lived experience partnership in healthcare.*

Lived Experience Insights Video Series

[Watch series \(~15 minutes\)](#) *Real stories from lived experience representatives about their experiences.*

Health Research Training

Version 2.0	Published 08.26	Review 08. 2027
-------------	-----------------	-----------------

Access training (30 minutes) *Introduction to lived experience involvement in health research.*

Storytelling Skills

Being able to share your lived experience powerfully, ethically, and safely is vital for many Level 2 activities.

For tips on effective Story Telling, [watch this video \(38 minutes\)](#) *Learn to communicate your story clearly and with impact (please note this is a North American resource).*

An advanced Storytelling course can be found here: [Can-SOLVE CKD Course \(12-15 hours\)](#) *In-depth module for developing and delivering your health story (please note this is a North American resource).*

Level 3 Advanced Training

For those stepping into lived experience-leader roles, committee participation, or strategic advocacy opportunities.

Training Overview

Level 3 activities require specific training tailored to each role. Your Lived Experience Engagement Coordinator will discuss the requirements and provide details during your one-on-one consultation.

Training may cover:

- Preparation for committee and advisory participation
- Consumer engagement principles and best practice approaches
- Role-specific skills and knowledge
- Confidentiality and ethical requirements
- Communication, collaboration and facilitation techniques
- Relevant policies, procedures and organisational expectations

All training is provided before you begin your Level 3 activities, with ongoing support available as needed.

Further lived experience engagement training opportunities can be explored through organisations such as the **Health Consumers Queensland** (<https://www.hcq.org.au/>)

Support and Recognition

Our Support for You

Financial Support

Version 2.0	Published 08.26	Review 08. 2027
-------------	-----------------	-----------------

We Reimburse:

- Transport and parking costs
- Meals during in-person events (when not provided)
- Accommodation for interstate/regional travel (pre-approved)

How to Claim: You will receive clear guidance on submitting reimbursement claims, including forms and timelines. Ask your coordinator if you are unsure about any expenses.

Wellbeing Support

Sharing your story and discussing blood cancer can be emotionally demanding. Your wellbeing matters to us.

Our Commitment:

- Regular check-ins to ensure you feel supported
- Respect for your boundaries and comfort levels
- Flexible participation options (online, phone, and in-person formats)
- Access to debriefing support when appropriate
- Resources for emotional and psychological wellbeing

Remember: You can take breaks, withdraw, or set boundaries around what you share at any time.

Recognition and Appreciation

Your participation in our program activities shapes the future of blood cancer awareness, our blood cancer services, research, and policy.

How We Recognise You:

- Public acknowledgement (with your consent)
- Invitations to networking and training events
- Letters of appreciation or certificates
- Payment or gift cards (where appropriate)
- VIP and professional development invitations

We welcome your feedback on how you would like your contributions to be recognised.

Activity Completion and Follow-up

What Happens After Each Activity

Your experience does not end when an activity concludes. We believe in closing the loop and ensuring you feel supported throughout your lived experience engagement journey.

Immediate Follow-up

After you complete any lived experience engagement activity, your Lived Experience Engagement Coordinator will reach out via text or email to:

- **Thank you** for your valuable contribution
- **Check in on your wellbeing** and see how you found the experience
- **Address any immediate concerns** or questions you might have

Formal Feedback Process

Within a few days, you will receive an experience feedback survey after most Level 2+ activities, and occasionally after Level 1 activities that support us to understand: experience and help shape service improvements.

- Your overall experience with the activity
- What worked well and what could be improved
- Any suggestions for future activities
- Your comfort level and support needs

Your feedback matters: All responses are collated and reviewed to continuously improve our lived experience engagement approach. If you raise any significant concerns, a staff member will follow up with you directly.

Measuring Impact Together

Your voice makes a difference - and we want to show you how.

Why We Measure Impact

We ensure your time, experience, and insights lead to real outcomes by:

- Understanding how lived experience input influences decisions
- Tracking progress against our strategic goals
- Identifying improvement opportunities
- Celebrating and sharing success stories

What We Track:

Version 2.0	Published 08.26	Review 08. 2027
-------------	-----------------	-----------------

- Whether lived experience input influenced decisions and outcomes
- Satisfaction and experience of lived experience partners
- Reach and engagement across different cultural and community groups
- Quality improvements from consumer involvement in services and programs
- Policy and advocacy wins informed by lived experience voices

How We Collect Data:

- Post-activity surveys and feedback forms
- End of year program feedback survey
- Storytelling and impact case studies
- Activity outcome summaries

How We Share the Results:

- Regular program updates to lived experience members

Our Commitment: We aim to be transparent about how your contributions are used and "close the loop" by sharing what decisions were informed by lived experience engagement.

Your Feedback Matters

Help us improve by:

- Completing post-activity evaluations
- Participating in annual program reviews
- Reaching out directly to your Lived Experience Engagement Coordinator
- Sharing suggestions during reflection sessions

All feedback is confidential and used to strengthen our program for future participants.

Resources

Frequently Asked Questions

Getting Started

Do I need special qualifications to participate?

No formal qualifications are required. Your lived experience, willingness to share, and interest in positive change are what matter most.

Version 2.0	Published 08.26	Review 08. 2027
-------------	-----------------	-----------------

How much time do I need to commit?

It depends on what you choose. Some activities are one-off (surveys, focus groups); others involve ongoing commitment (committees, advocacy roles). You decide what works for you and can change over time.

Is training involved?

For most activities, no formal training is required. You will receive guidance and support tailored to each activity. Most Level 3 activities require mandatory training to ensure you feel confident and prepared.

Participation

Can I choose what activities to be involved in?

Absolutely. You are in control of how and when you participate. We will match opportunities to your interests, background, and availability - but it is always your choice.

What if I need to take a break?

That is completely okay. Life happens, and we understand. You can pause or step back temporarily or long-term - just let us know. We will stay in touch if you would like to re-engage later.

Can I participate if I am based in a regional or remote area?

Yes! Many activities are accessible online, and we are committed to ensuring participation from diverse locations. We will work with you to address any barriers.

Compensation and Recognition

Is my contribution paid or reimbursed?

We reimburse pre-approved out-of-pocket expenses (travel, printing costs, etc.). Some opportunities may offer modest payment or honorariums for considerable time commitments.

Will my story be shared publicly?

Not without your consent. We respect your privacy and always seek permission before sharing anything identifiable. You choose how and when to share your story.

How will I know my contribution made a difference?

We are committed to "closing the loop" by showing you how your input was used through follow-up reports, summaries, or personal updates.

Helpful Resources

Getting Support

Version 2.0	Published 08.26	Review 08. 2027
-------------	-----------------	-----------------

- Provide feedback on activities or services: [Contact us](#)
- Learn about our services: [How we can help](#)

Skill Development Resources

- Partnering with Lived Experience Guide: [Download PDF](#)
- Lived Experience Insights Videos: [Watch series](#)

Program Information

- Lived experience e-noticeboard: Check monthly for new opportunities, click [here](#) to access
- WhatsApp Community: Check weekly for updates to the CEP and newly advertised opportunities, click [here](#) to join

Contact Information

Lived Experience Engagement Coordinator

Your main point of contact for:

- Questions about the program
- Updating your profile
- Support with activities
- General guidance and assistance

The Lived Experience Engagement Program Manager also supports the program's governance and operation and may be involved in strategic advocacy, leadership development, escalation of concerns, and program-related enquiries.

Support

If you feel unsafe, uncomfortable, or need immediate assistance, please reach out to your Lived Experience Engagement Coordinator. We are here to listen to and support you.

Our Ongoing Commitment to You

We are building a model of lived experience engagement that is transparent, impactful, and person-centered. Your input will help shape that journey.

Together, we can ensure that lived experience engagement at the Leukaemia Foundation reflects and respects the full diversity of those affected by blood cancer.

Thank you for being part of this important work. Your voice matters, your experience has value, and your contribution is making a real difference in the blood cancer community.

This handbook is a living document that evolves based on your feedback and our shared learning. We welcome your suggestions for improvement.

Version 2.0	Published 08.26	Review 08. 2027
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We acknowledge and thank the lived experience individuals who generously contributed their insights in shaping this Handbook, which has also undergone lived experience input and review.

