

Engage Community Charter

Welcome to Engage

Engage is a shared space for people with lived experience of children and young people's cancer to help shape research, care, services and policy.

Our aim is to create a supportive, inclusive and meaningful community where lived experience can contribute to positive change for children, young people and families.

By joining Engage, all members agree to follow the principles set out in this charter.

What you can expect from Engage

The Engage team is committed to providing a platform that is:

- Respectful and inclusive – where all members are treated with dignity, kindness and respect.
- Safe and supportive – recognising that lived experience involvement can sometimes be emotional and ensuring members can participate free from harassment, discrimination or judgement.
- Meaningful and purposeful – sharing opportunities that have a clear purpose and genuine potential to influence research, services, policy or practice.
- Transparent – being open about how the platform works and the role we play in facilitating opportunities.
- Responsive – listening to feedback and continuously improving the platform.
- Well managed – taking appropriate action where behaviour undermines the safety or wellbeing of others.

What we ask of Engage members

To help create a positive experience for everyone, we ask all members to:

- Be respectful of others, even where experiences or opinions differ.
- Be mindful of lived experience, recognising that discussions may be personal or emotionally challenging.
- Help create a safe community free from bullying, harassment, discrimination or personal attacks.
- Respect privacy and confidentiality, including your own and that of others.
- Engage constructively, keeping contributions relevant, thoughtful and made in good faith.
- Respect boundaries, recognising that everyone has different levels of comfort, availability and readiness to participate.

- Participate in evaluation and feedback requests to help Engage develop and improve.

The purpose of Engage

Engage is a lived experience involvement platform designed to support collaboration, learning and participation in research, policy, service improvement and advocacy.

Engage is not a medical advice forum.

While members may draw upon their own experiences, the platform is not intended for:

- Seeking individual medical advice or treatment recommendations
- Discussing personal clinical circumstances in detail
- Accessing urgent health, welfare or crisis support
- Replacing conversations with healthcare professionals

If you have concerns about your own or your child's health, treatment or wellbeing, please contact your healthcare team or an appropriate support service.

Looking after yourself

Lived experience involvement can be rewarding, empowering and meaningful. However, sharing experiences and discussing cancer-related topics can sometimes be emotionally challenging.

We encourage all members to:

- Participate at a pace that feels right for them.
- Consider whether a particular opportunity or topic feels manageable at that point in time.
- Take breaks or step back when needed.
- Set boundaries around what they do and do not wish to share.
- Seek support from family, friends, support services or healthcare professionals if participation brings up difficult emotions.
- Show compassion and understanding towards other members who may be finding discussions challenging.

Your wellbeing should always come before participation. It is okay to say no, take a break or change your level of involvement at any time.

External opportunities

Engage may promote opportunities developed and delivered by external organisations, including researchers, healthcare organisations, charities, public bodies and commercial partners.

While we encourage all organisations using Engage to follow good practice for lived experience involvement, responsibility for delivering these opportunities lies with the organisation leading the work.

Members should be aware that:

- Engage does not design, manage or oversee all external projects.
- We cannot guarantee the quality, delivery, outcomes or impact of opportunities delivered by third parties.
- Recruitment, participation, reimbursement and project decisions are determined by the organisation running the opportunity.
- Members who decide to participate do so directly with the host organisation.

When we may take action

To protect the wider community, the Engage team may remove content, restrict participation or suspend accounts where behaviour is inconsistent with this charter or risks the safety and wellbeing of other users.

Where possible, we will seek to resolve concerns fairly, proportionately and constructively.

Our shared commitment

Engage is built on respect, collaboration and the belief that lived experience can drive meaningful change.

By being part of this community, we commit to supporting one another, using lived experience thoughtfully and helping ensure that the voices of children, young people and families continue to influence research, care and policy.

Together, we can turn lived experience into lasting change.

By creating an account and using Engage, you acknowledge that you have read and agree to follow this Community Charter.