

Consumer Involvement in Research

Emotional Safety

Emotional challenges may arise during consumer involvement in research. It is important to maintain emotional wellbeing and have access to strategies and support contacts.

Disclaimer: This resource was developed for the Daffodil Centre. If you are accessing this resource from another organisation, please consider your own institutional context and policies when applying the information provided.

For consumers

Engaging in research can bring up challenging emotions and thoughts. It is important to acknowledge these feelings and take steps to maintain emotional wellbeing.

Things to consider:

- Participating in research projects may evoke difficult past experiences or worries about cancer recurrence or progression, or grief from loss of a loved one. Recognise that such emotions are valid and natural.
- These emotions may arise unexpectedly, and it is okay to let your research team know if you need to take a break to process them.
- If you feel overwhelmed, consider speaking to a counsellor or joining a support group.

Find support

Consumers

Cancer Council Support Line: call 13 11 20 or visit cancerCouncil.com.au.

Researchers

Daffodil Centre researchers have access to an Employee Assistance Program (EAP) through their employer.

University of Sydney staff

EAP Provider: Converge
Tel: 1300 687 327
Learn more: [staff intranet](#)



Download app

Cancer Council NSW staff

EAP Provider: Sonder
Tel: 1800 234 560
Learn more: [Dougai](#)



Download app

For researchers

Working closely with consumers can also bring emotional challenges, especially if you have personal experiences with cancer or develop meaningful connections with consumer partners.

Things to consider:

- It is important to follow the consumer's lead to ensure that their emotional comfort is always maintained. Be mindful that retelling stories of illness experience can be triggering to consumers and emotionally exhausting.
- You may feel saddened by your consumer partners' circumstances, especially if you have worked with them for a long period and their health worsens.
- Maintaining emotional boundaries can be difficult. This is a natural by-product of empathy, as you often need to think in their shoes. However, it is important to manage these emotions effectively to sustain a productive relationship with your consumer partners.
- Past experiences with family or friends affected by cancer may also resurface during engagement.
- It is okay to talk about these emotions. Speak to a colleague or manager for support.
- If needed, consider seeking further professional support.

For managers / project leads

In some cases, a consumer partner may become ill, which can be difficult for your research team and other consumer partners. It is important to assess whether your team would benefit from a group debrief.

Junior staff may be particularly susceptible to becoming distressed but may not realise that they can discuss this or seek support through their EAP provider. Open discussions and sharing experiences can help normalise challenging emotions and provide an avenue for coping. Safety plans, which provide procedures to support emotional safety for consumers/researchers, are encouraged and should be developed as part of the research protocol.