

Living Experience
Engagement in DTA
Activities
Outline and FAQs



Dementia
Training
Australia®

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Overview

DTA recognises and values the living experience expertise of people diagnosed with dementia and their carers or support partners. The involvement of people living with dementia in program design, development, and delivery will make DTA training more relevant, engaging, and effective, and will deliver stronger capacity building outcomes.

DTA may seek advice from people with living experience of dementia advice on a variety of areas, including:

- Educational resources for the dementia workforce
- Dementia care quality and safety
- Priorities and desired outcomes of people living with dementia and their families and carers
- Strategic directions of DTA.

Consultation/engagement with people with living experience of dementia may take the form of:

- call for written submissions and surveys
- public meetings and workshops
- focus groups or individual interviews
- online consultations, including webinars

Purpose

The purpose of consultation/co-design is to strengthen and improve DTA processes, programs, projects, and resources by including the perspective of living experience which supports DTA's vision, mission, and values. Consultation with people with living experience of dementia will allow DTA to:

- Design and deliver training that includes perspectives and desired outcomes for people living with dementia including carers/support partners
- Understand what matters to people living with dementia and their families and carers to enable the greatest possible positive impact of our training and resources
- Set education and training standards for the dementia care workforce that support best outcomes as defined by people with living experience of dementia
- Build diverse communities of practice that include people with living experience
- Adapt to progressive expectations of equity, diversity and inclusion in education practice

Who is Eligible to Participate?

A range of people with living experience of dementia may be approached for consultation activities. People with living experience of dementia will be selected based on their:

- Experience as people living with dementia or their care partners
- Other relevant skills and expertise
- Ability to represent the views of a cross section of the dementia care landscape
- Availability, willingness, and capacity to contribute

People with living experience of dementia will usually be people living with a diagnosis of dementia and/or those who have experience supporting people living with dementia.

People with living experience of dementia will be engaged on a project-by-project basis.

How Can I Get Involved?

DTA will circulate calls for involvement through various channels including: The Dementia Australia Dementia Advocates program; Dementia Alliance International; Previous DTA consultation activities; DTA staff networks; Other consumer networks and groups.

Will Participants Be Paid?

DTA values the input of people with living experience of dementia and recognises that they are not being professionally paid for their time they commit to DTA activities. Where possible, a financial honorarium of participation (usually a visa or Mastercard gift card) will be offered to people with living experience of dementia who are invited to contribute to DTA activities.

DTA uses an amount of \$100 per 1-1.5 hours engagement (may be meeting, review of material etc) as a guide for the recognition of contribution.

Where appropriate, out of pocket expenses will also be reimbursed. This may include:

- Travel to and from meetings
- Accommodation costs for attending meetings
- Meals and drinks costs whilst away from home attending meetings

- Other reasonable out of pocket expenses incurred to attend DTA engagement activities

Payment and reimbursement details will be communicated by DTA to participants prior to their commitment to an activity.

DTA will endeavour to seek funding for engagement activities to ensure that living experience involvement is prioritised in program development.

Will My Carer or Support Partner's Costs be Covered?

DTA recognises that the person living with dementia may require assistance from a carer/support partner to attend DTA activities. With prior agreement DTA will cover out of pocket expenses for the carer/support person who is supporting the person living with dementia to attend DTA activities.

I Live in a Rural and Remote Area; Can I Still Participate?

DTA strives to provide a nationally consistent and equitable approach. Where possible engagement will be facilitated via:

- Web-based platform including webinars, webcasting, online forums, surveys
- Video/Telephone/Conference Calls
- On occasion, face to face may be the preferred approach and, in this instance, DTA will work with people with living experience of dementia participants to facilitate equitable access to consultation opportunities.

What is the Process to Consent to Participate?

Written consent will be gained from any person with living experience of dementia who volunteers to participate in a DTA engagement. The consent may be proxy consent by a person with legal powers to provide consent on behalf of the person living with dementia if appropriate.

A request for consent will be accompanied with an outline of the DTA activity the person is being invited to participate in and your DTA contact will be available for a conversation to ensure you understand what you are committing to.

I Agreed to Participate but I Changed My Mind. What Should I Do?

Participants can withdraw their consent to participate in any activity at any time. If you have changed your mind or your circumstances have changed you should feel free to abstain from any activity. As a courtesy, please let your project contact person know of the change.

Privacy

Consent forms and personal details will be stored in accordance with UOW and legislative data protection policies.

A person's persona/contact details will not be shared with any third party or for any other purpose without prior agreement.

Living with dementia can be a difficult experience, and a person may feel stigmatised by their diagnosis. DTA will support a person to ensure their dignity, privacy and respect is always maintained whilst engaging with DTA.

Safeguarding

DTA will create an environment that ensures people with living experience of dementia are respected, can share their opinions and advice without judgement or reprisal and feel valued for their contribution.

Living with dementia creates individual different cognitive disabilities. DTA will utilise inclusive and enabling practices to ensure the person living with dementia has accessibility to material or meetings in a way that recognises their impairments and that meets their needs. This includes scheduling of meetings, meeting duration, providing printed material in accessible design before the meeting, providing reminders and sharing minutes or notes from meetings held. Discussing personal issues may cause emotional distress for the person with living experience of dementia. It is important that any DTA program/project engaging people with living experience of dementia has information available to share on counselling, support services or where a person may seek assistance if they are experiencing distress.

Complaints

Any complaint from a person with living experience of dementia involved in a DTA engagement will be managed as per the DTA complaints procedure. In addition, the Executive Director/Associate Executive Director will be notified immediately if a complaint is received.