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**SPIN DEMENTIA
NETWORK⁺**

Sustainable Prevention,
Innovation and Involvement
for Dementia



Core Lived Experience Group (CLEG) Terms of Reference

Terms of Reference help members to understand the purpose structure and expectations of the CLEG.

The SPIN Dementia Network+ was established in 2024 to build a network around our understanding of brain health, ways to reduce the risk of dementia, delay the onset of symptoms, and lessen the impact of dementia. Public, Patient Involvement and Engagement (PPIE) is fundamental to the Network at all levels and across all activities. A key Network objective is to recruit a Core Lived Experience Group formed of ten members who become actively involved in activities throughout the Network.

What does the Core Lived Experience Group do?

Members of the Group will get involved in a range of activities that may include:

- Attending and contributing at a variety of meetings including the termly CLEG meetings
- Reviewing and commenting on research abstracts and proposals
- Involvement in funding application panels
- Review and editing of resources
- Attending and participating in a variety workshops, conferences and activities, online and in person
- Involvement in case studies and film projects
- Work with Early Career Researchers

- Involvement in Research projects
- Telling others about the work of the Network

Expectations of members

1. Whilst there is an invitation to attend termly meetings, all involvement is entirely voluntary, and members can refuse to undertake any tasks or participate in activities without offering any explanation
2. If members would like to leave the group at any time, they are free to do so by emailing the Public Involvement Co-ordinator, meaning they immediately will be removed from all activities email lists
3. The group will meet mostly online because members span across the UK
4. There is an expectation that members will ask for help and support if anything is unclear and for adjustments that can aid involvement
5. Members should contact the Public Involvement Coordinator when something is not working well, or they wish to submit a complaint.

What Members can expect from the Network

1. To be welcomed, respected and listened to
2. For staff and all Network members you work with to consider any accessibility requirement or additional needs you may have
3. For staff and all Network members to recognise public involvement as an essential part of their work
4. To be able to contact a member of staff by email: debragingell@exeter.ac.uk
5. For staff to consider any accessibility or additional needs you may have
6. To be kept up to date with project progress and get feedback on meetings you attend
7. To be paid for your time and any additional costs you have fulfilling your role; like travel or postage

Payment and Compensation

Members will receive acknowledgement payment for all voluntary involvement as well as any expenses incurred. Payments are currently in line with University of Exeter' PenARC project. CLEG members will be made aware of any changes to payments.

CLEG members will be made aware that payments may affect their benefits and that they are liable for their own tax payments when they join the group. The Public Involvement Co-ordinator will work closely with members to match payments to the agreed activity.