

Tips and Strategies for Engaging People with Lived Experience of Dementia in Research Meetings

Ellen Snowball, Inbal Itzhak, Emma Lanza, Myrna Norman, Catherine Ann Kelly, Christine Thelker, Wayne Hykaway, Heather Eagleson, Linda Grossman, Rosette Loughlin, Faye Forbes, Karen Myers Barnett, Janet Rocheleau, Katherine S. McGilton, Jennifer Bethell



Engage Early and Hold Frequent Meetings

Involve people with lived experience in planning committees for events. Facilitate meetings between speakers (including people with lived experience) and researchers.



Provide Support

Provide support – make sure people have what they need to participate (e.g., technical support, documents, etc). Offer to pay expenses of the support person for travel or for support required at home.



Create Multiple Roles

Offer different kinds of roles, (e.g., panelists, reviewers, discussants). Be clear on roles and expectations.



Include Diverse Perspectives

Think about how to represent diverse experiences of dementia, demographic characteristics and research background (e.g., experience of research).



Plan for Informal and Formal Interactions

Create opportunities that allow people to interact informally (e.g., coffee breaks, Q&A periods) as well as within the program.



Plan for Frequent Breaks

Plan for physical break spaces (e.g., hotel rooms) and make time for frequent breaks in the agenda. Accommodate for missed information.



Encourage Participation

Encourage lived experience participation in any aspect of the program. However, make note of sessions that will be particularly technical, for specialized audience. Ask presenters to prepare messages in plain language for lived experience audiences.



Provide Compensation and Prepay Expenses

Compensate people with lived experience who get involved. Make arrangements to prepay expenses (e.g., hotel, flights) wherever possible.



Use Accessible Language and Spaces

Use accessible, person-centred language in all communications. Consider physical and virtual spaces that are accessible (e.g., wheelchair accessible, easy to use, etc.). Require minimal travel between spaces.



Evaluate from Different Perspectives

Evaluate the contributions of the lived experience perspectives in the event for the audience and invite them to reflect on it (e.g., include feedback survey questions).



These tips were gathered from EPLED Advisory Group members, researchers, and research administrators based on their engagement experience at CCNA's Partners Forum and Science Days. For more information watch our video by scanning the QR code or contact us below.

ellen.snowball@uhn.ca | www.epled.ca