

Engagement of People with Lived Experience of Dementia (EPLED) in research Reference list

1) Language about dementia and writing for different audiences

Alzheimer Society of Canada	Person-centred language guidelines
Alzheimer Australia	Dementia language guidelines
Alzheimer's Society (UK)	Positive language. An Alzheimer's Society guide to talking about dementia
Alzheimer's Society (UK)	Advice for grant applicants from people affected by dementia
Behavioural Supports Ontario (BSO)	Person Centred Language Initiative
The Dementia Engagement and Empowerment Project	Dementia words matter: Guidelines on language about dementia
NIHR INVOLVE	Make it clear. Writing and using plain English summaries
SickKids	Plain Language Writing Checklist

2) Patient engagement and dementia-friendly research practices

Alzheimer Europe	Overcoming ethical challenges affecting the involvement of people with dementia in research: recognizing diversity and promoting inclusive research
Alzheimer Society of Canada	Meaningful engagement of people with dementia. A Resource Guide.
Alzheimer's Society (UK)	Dementia-friendly templates: examples and tips Tips for dementia-friendly documents Methods for finding out about the experience of people with dementia Includes sections on: <ul style="list-style-type: none">• Tips to give a dementia-friendly welcome at your activity• Surveys of people with dementia• Working with questions and data
The Dementia Engagement and Empowerment Project	DEEP guides for organisations and communities Includes sections on: <ul style="list-style-type: none">• Choosing a dementia-friendly meeting space• Involving people with dementia as members of steering or advisory groups• Guide for conference presenters• Involving people with dementia at conferences and events• Tips for consulting people with dementia about written documents

Partnerships in Dementia Care	Authentic Partnerships
Scottish Dementia Working Group	Dementia friendly meetings
Scottish Dementia Working Group	Core principles for involving people with dementia in research

Journal Articles

Bethell J, Commisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, Wighton MB, Hammel J, Doyle E, Nadeau S, McGilton KS. Patient engagement in research related to dementia: A scoping review. *Dementia (London)*. 2018 Nov;17(8):944-975. <https://doi.org/10.1177/1471301218789292>

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Murray Alzheimer Research and Education Program (MAREP) and Supporting Inclusion through Intergenerational Partnerships (SIIP)
[Become a research partner](#)

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3) Patient engagement - general

Canadian Institutes of Health Research (CIHR)	SPOR Patient engagement framework
	Guide to Researcher and Knowledge-User Collaboration in Health Research
	Patient Engagement in Research Resources
	Ethics Guidance for Developing Partnerships with Patients and Researchers
Centre of Excellence on Partnership with Patients and the Public	Patient and public engagement. Evaluation Toolkit. Register for monthly evidence feed
Clinical Trials Ontario	Decision Aids for Patient Partner Engagement with Clinical Trials
George & Fay Yee Centre for Healthcare Innovation (CHI)	Engagement methods (interactive map tool)
NIHR INVOLVE	Briefing notes for researchers: public involvement in NHS, public health and social care research
NIHR INVOLVE	Supplements: <ul style="list-style-type: none">• Public involvement in systematic reviews• Strategies for diversity and inclusion in public involvement• Public involvement in clinical trials Case studies Templates
SPOR Support Units (includes links to provinces)	https://cihr-irsc.gc.ca/e/45859.html
Saskatchewan Centre for Patient Oriented Research	Onboarding Guide for Patient-Oriented Research Teams – General Information for Researchers. Onboarding Guide for Patient-Oriented Research Teams – General Information for Patient Partners.
CIHR - Institute of Musculoskeletal Health and Arthritis	Patient Engagement Resources

Journal articles

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4) Patient engagement – approaches to compensation and reimbursement

Canadian Institutes of Health Research (CIHR)	Considerations when paying patient partners in research
Change Foundation	Should money come into it?
NIHR INVOLVE	Payment and recognition for public involvement
SPOR Networks in Chronic Disease	Recommendations on Patient Engagement Compensation

Richards D.P., Jordan I, Strain K, Press Z. (2018) Patient partner compensation in research and health care: the patient perspective on why and how. *Patient Experience Journal*. 5(2). <https://doi.org/10.35680/2372-0247.1334>

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Version date: November 23rd 2022

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