

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

1) Language about dementia and writing for different audiences

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| 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

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| 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 for a dementia-friendly welcome at your activity or event• 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 |

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| 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

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| 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 |

NIHR|INVOLVE

[Supplements:](#)

- 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>

Journal articles

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4) Patient engagement – approaches to compensation and reimbursement

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| 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 |

Version date: February 14th 2022

Richards DP, 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).
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