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

Reference list

## **Language about dementia and writing for different audiences**

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| --- | --- |
| Alzheimer Society of Canada | [Person-centred language guidelines](https://alzheimer.ca/sites/default/files/files/national/culture-change/person-centred-language-guidelines.pdf) |
| Alzheimer Australia | [Dementia language guidelines](https://www.dementia.org.au/files/resources/dementia-language-guidelines.pdf) |
| Alzheimer’s Society (UK) | [Positive language. An Alzheimer’s Society guide to talking about dementia](https://www.alzheimers.org.uk/sites/default/files/2018-09/Positive%20language%20guide_0.pdf) |
| Alzheimer’s Society (UK) | [Advice for grant applicants from people affected by dementia](https://www.alzheimers.org.uk/research/researchers/grant-application-advice-from-people-affected-dementia) |
| The Dementia Engagement and Empowerment Project | [Dementia words matter: Guidelines on language about dementia](http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf) |
| NIHR|INVOLVE | [Make it clear. Writing and using plain English summaries](https://www.invo.org.uk/wp-content/uploads/2014/05/MICA4flyer.pdf) |

## **Patient engagement and dementia-friendly research practices**

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| Alzheimer Society of Canada | [Meaningful engagement of people with dementia. A Resource Guide.](https://alzheimer.ca/sites/default/files/files/national/meaningful-engagement/meaningful-engagement-of-people-with-dementia.pdf) |
| Alzheimer’s Society (UK) | [Methods for finding out about the experience of people with dementia](https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods)Includes sections on:* [Tips for a dementia-friendly welcome at your activity or event](https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/tips-dementia-friendly-surveys)
* [Surveys of people with dementia](https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods/surveys)
* [Working with questions and data](https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/working-with-data)
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| The Dementia Engagement and Empowerment Project | [DEEP guides for organisations and communities](https://www.dementiavoices.org.uk/deep-guides/for-organisations-and-communities/)Includes sections on:* [Choosing a dementia-friendly meeting space](https://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf)
* [Involving people with dementia as members of steering or advisory groups](https://www.dementiavoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf)
* [Guide for conference presenters](https://www.dementiavoices.org.uk/wp-content/uploads/2013/11/Guide-for-conference-presenters.pdf)
* [Involving people with dementia at conferences and events](https://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Conferences-and-events.pdf)
* [Tips for consulting people with dementia about written documents](https://www.dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf)
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| Partnerships in Dementia Care | [Authentic Partnerships](https://uwaterloo.ca/partnerships-in-dementia-care/sites/ca.partnerships-in-dementia-care/files/uploads/files/authentic_partnerships_fact_sheet.pdf) |
| Scottish Dementia Working Group | [Dementia friendly meetings](https://www.alzscot.org/sites/default/files/2019-07/Dementia%20Friendly%20Meetings.pdf) |
| Scottish Dementia Working Group | [Core principles for involving people with dementia in research](https://www.alzscot.org/sites/default/files/2019-07/Core%20Principles.pdf) |

### Journal Articles

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Morbey, H., Harding, A.J.E., Swarbrick, C. et al. (2019). Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development. Trials 20, 12. <https://doi.org/10.1186/s13063-018-3069-6>

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## **Patient engagement - general**

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| Canadian Institutes of Health Research (CIHR) | [SPOR Patient engagement framework](https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf) |
| Canadian Institutes of Health Research (CIHR) | [Guide to Researcher and Knowledge-User Collaboration in Health Research](https://cihr-irsc.gc.ca/e/documents/Guide_to_Researcher_and_KU_Collaboration.pdf)  |
| Canadian Institutes of Health Research (CIHR) | [Patient Engagement in Research Resources](https://cihr-irsc.gc.ca/e/51916.html) |
| Centre of Excellence on Partnership with Patients and the Public | [Patient and public engagement. Evaluation Toolkit.](https://ceppp.ca/en/collaborations/evaluation-toolkit/)Register for [monthly evidence feed](https://ceppp.us19.list-manage.com/subscribe?u=fe6724e4a3bbbac315fa15dd6&id=a562f9236b) |
| George & Fay Yee Centre for Healthcare Innovation (CHI) | [Engagement methods](https://chimb.ca/sub-sites/1-patient-engagement?page=75-engagement-methods) (interactive map tool) |
| NIHR|INVOLVE | [Briefing notes for researchers: public involvement in NHS, public health and social care research](https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf) |
| NIHR|INVOLVE | [Supplements:](https://www.invo.org.uk/supplements-to-resource-for-researchers/) * Public involvement in systematic reviews
* Strategies for diversity and inclusion in public involvement
* Public involvement in clinical trials

[Case studies](https://www.invo.org.uk/resource-for-researchers-case-studies/)[Templates](https://www.invo.org.uk/resource-for-researchers-templates/) |
| SPOR Support Units (includes links to provinces) | <https://cihr-irsc.gc.ca/e/45859.html>  |

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## **Patient engagement – approaches to compensation and reimbursement**

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| Canadian Institutes of Health Research (CIHR) | [Considerations when paying patient partners in research](https://cihr-irsc.gc.ca/e/51466.html) |
| Change Foundation | [Should money come into it?](https://changefoundation.ca/wp-content/uploads/2016/05/Should-money-come-into-it.pdf)  |
| NIHR|INVOLVE | [Payment and recognition for public involvement](https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/) |
| SPOR Networks in Chronic Disease | [Recommendations on Patient Engagement Compensation](https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT_FINAL-1.pdf) |

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