**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) |
| 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) |
| 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

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>

Burton A, Ogden M, Cooper C. (2019) Planning and enabling meaningful patient and public involvement in dementia research. Curr Opin Psychiatry. 32(6):557-562. <https://doi.org/10.1097/YCO.0000000000000548>

Di Lorito, C., Birt, L., Poland, F., Csipke, E., Gove, D., Diaz-Ponce, A., & Orrell, M. (2017) A synthesis of the evidence on peer research with potentially vulnerable adults: How this relates to dementia. International Journal of Geriatric Psychiatry, 32(1), 58–67. <https://doi.org/10.1002/gps.4577>

Di Lorito, C., Godfrey, M., Dunlop, M., Bosco, A., Pollock, K., van der Wardt, V., Harwood, R.H. (2020). Adding to the knowledge on Patient and Public Involvement: Reflections from an experience of co-research with carers of people with dementia. Health Expect. <https://doi.org/10.1111/hex.13049>

Dr€oes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K.,. . . Charras, K. (2017) Social health and dementia: A European consensus on the operationalization of the concept and directions for research and practice. Aging & Mental Health, 21(1), 4–17. <https://doi.org/10.1080/13607863.2016.1254596>

Dupuis, S. L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., & Sadler, L. (2012) Moving beyond patient and client approaches: Mobilizing ‘authentic partnerships’ in dementia care, support and services. Dementia, 11(4), 427–452. <https://doi.org/10.1177/1471301211421063>

Frank L, Shubeck E, Schicker M, Webb T, Maslow K, Gitlin L, et al. (2020) Contributions of persons living with dementia to scientific research meetings: best practices from the national research summit on care, services and supports for persons with dementia and their caregivers. Am J Geriatr Psychiatry. 28(4):421-430. <https://doi.org/10.1016/j.jagp.2019.10.014>

Goeman D, King J, Koch S. (2016) Development of a model of dementia support and pathway for culturally and linguistically diverse communities using co-creation and participatory action research. BMJ Open. 6:e013064. <https://doi.org/10.1136/bmjopen-2016-013064>

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R.,. . . European Working Group of People with Dementia. (2018) Alzheimer Europe’s position on involving people with dementia in research through PPI (patient and public involvement). Aging & Mental Health, 22(6), 723–729. <https://doi.org/10.1080/13607863.2017.1317334>

Iliffe S, McGrath T, Mitchell D. The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies. (2013) Health Expect. 16(4):351-61. <https://doi.org/10.1111/j.1369-7625.2011.00728.x>

Litherland R, Burton J, Cheeseman M, Campbell D2, Hawkins M, Hawkins T, Oliver K, Scott D, Ward J, Nelis SM, Quinn C, Victor C, Clare L. Reflections on PPI from the 'Action on Living Well: Asking You' advisory network of people with dementia and carers as part of the IDEAL study. (2018) Dementia (London). 17(8):1035-1044. <https://doi.org/10.1177/1471301218789309>

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>

Miah J, Dawes P, Edwards S, Leroi I, Starling B, Parsons S. Patient and public involvement in dementia research in the European Union: a scoping review. (2019) BMC Geriatr. 19(1):220. <https://doi.org/10.1186/s12877-019-1217-9>

Mockford, C., Murray, M., Seers, K., Oyebode, J., Grant, R., Boex, S., . . . Suleman, R. (2016). A SHARED study-the benefits and costs of setting up a health research study involving lay coresearchers and how we overcame the challenges. Research Involvement & Engagement, 2, 8. <https://doi.org/10.1186/s40900-016-0021-3>

Parveen S, Barker S, Kaur R, Kerry F, Mitchell W, Happs A, Fry G, Morrison V, Fortinsky R, Oyebode JR. (2018) Involving minority ethnic communities and diverse experts by experience in dementia research: The Caregiving HOPE Study. Dementia (London). 17(8):990-1000. <https://doi.org/10.1177/1471301218789558>

Phillipson, L., & Hammond, A. (2018). More Than Talking: A Scoping Review of Innovative Approaches to Qualitative Research Involving People With Dementia. International Journal of Qualitative Methods. <https://doi.org/10.1177/1609406918782784>

Phinney A. (2008) Promoting self-care through knowledge translation: a way to reach people with early-stage dementia. Can J Nurs Res. 40(3):135-9.

Roberts C, Rochford-Brennan H, Goodrick J, Gove D, Diaz-Ponce A, Georges J. (2020) Our reflections of Patient and Public Involvement in research as members of the European Working Group of People with Dementia. Dementia (London). 19(1):10-17. <https://doi.org/10.1177/1471301219876402>

Scottish Dementia Working Group Research Sub-Group, UK. Core principles for involving people with dementia in research: innovative practice. (2014) Dementia (London). 13(5):680-5. <https://doi.org/10.1177/1471301214533255>

Span M, Hettinga M, Groen-van de Ven L, Jukema J, Janssen R, Vernooij-Dassen M, Eefsting J, Smits C. Involving people with dementia in developing an interactive web tool for shared decision-making: experiences with a participatory design approach. Disabil Rehabil. 2018 Jun;40(12):1410-1420. <https://doi.org/10.1080/09638288.2017.1298162>

Swaffer K. Co-production and engagement of people with dementia: The issue of ethics and creative or intellectual copyright. Dementia (London). 2016 Nov;15(6):1319-1325. <https://doi.org/10.1177/1471301216659213>

Swarbrick CM, Open Doors, Scottish Dementia Working Group, Educate, Davis K, Keady J. Visioning change: Co-producing a model of involvement and engagement in research (Innovative Practice). Dementia (London). 2019 Oct-Nov;18(7-8):3165-3172. <https://doi.org/10.1177/1471301216674559>

Waite J, Poland F, Charlesworth G. Facilitators and barriers to co-research by people with dementia and academic researchers: Findings from a qualitative study. (2019) Health Expect. 22(4):761-771. <https://doi.org/10.1111/hex.12891>

Young A, Ferguson-Coleman E, Keady J. (2018) Authentic public and patient involvement with Deaf sign language users: It is not just about language access. Dementia (London). 17(8):1001-1010. <https://doi.org/10.1177/1471301218789567>

## **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> |

### Journal articles

Backhouse T, Kenkmann A, Lane K, Penhale B, Poland F, Killett A. (2016) Older care-home residents as collaborators or advisors in research: a systematic review. Age Ageing. 2016 May;45(3):337-45. <https://doi.org/10.1093/ageing/afv201>

Bird, M., Ouellette, C., Whitmore, C., Li, L., Nair, K., McGillion, M.H., Yost, J., Banfield, L., Campbell, E., Carroll, S.L. (2020). Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. Health Expect. <https://doi.org/10.1111/hex.13040>

Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Denis, J. L., & Pomey, M. P. (2018). Engaging patients to improve quality of care: a systematic review. Implementation science : IS, 13(1), 98. <https://doi.org/10.1186/s13012-018-0784-z>

Boivin A, L'Espérance A, Gauvin FP, Dumez V, Macaulay AC, Lehoux P, Abelson J. Patient and public engagement in research and health system decision making: A systematic review of evaluation tools. Health Expect. 2018 Dec;21(6):1075-1084. <https://doi.org/10.1111/hex.12804>

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., Brozek, I., & Hughes, C. (2014). Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. BMC medical research methodology, 14, 42. <https://doi.org/10.1186/1471-2288-14-42>

Crocker JC, Ricci-Cabello I, Parker A, Hirst JA, Chant A, Petit-Zeman S, Evans D, Rees S. Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis. (2018) BMJ. 363:k4738. <https://doi.org/10.1136/bmj.k4738>

Gordon, J., Franklin, S. & Eltringham, S.A. (2018) Service user reflections on the impact of involvement in research. Res Involv Engagem 4, 11. <https://doi.org/10.1186/s40900-018-0095-1>

Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, Chant A. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. (2019) Health Expect. 22(4):785-801. <https://doi.org/10.1111/hex.12888>

Howe, A., Mathie, E., Munday, D. et al. (2017) Learning to work together – lessons from a reflective analysis of a research project on public involvement. Res Involv Engagem 3, 1. <https://doi.org/10.1186/s40900-016-0051-x>

Leese J, Macdonald G, Kerr S, et al. (2018) ’Adding another spinning plate to an already busy life’. Benefits and risks in patient partner–researcher relationships: a qualitative study of patient partners’ experiences in a Canadian health research setting. BMJ Open. 8:e022154. <https://doi.org/10.1136/bmjopen-2018-022154>

Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research BMJ 2017; 358 :j3453 <https://doi.org/10.1136/bmj.j3453>

## **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) |

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). <https://doi.org/10.35680/2372-0247.1334>