

Engagement of People with Lived Experience of Dementia (EPLD) 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

The Alberta SPOR SUPPORT Unit (AbSPOR)	How-to Guide for Patients How-to Guide for Researchers
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<ul style="list-style-type: none">• 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](#)

The George and Faye Yee Centre for Healthcare Innovation	Readiness to Engage Workbook
Newfoundland & Labrador SUPPORT (NL SUPPORT)	Patient and Public Engagement Planning Template
Partnerships in Dementia Care	Authentic Partnerships
Saskatchewan Centre for Patient Oriented Research (SCPOR)	PORLET & IRLET: Tools for Measuring Patient Engagement
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>

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>

Diaz, A., Gove, D., Nelson, M., Smith, M., Tochel, C., Bintener, C., Ly, A., Bexelius, C., Gustavsson, A., Georges, J., Gallacher, J., & Sudlow, C. (2021). Conducting public involvement in dementia research: The contribution of the European Working Group of People with Dementia to the ROADMAP project. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 24(3), 757-765. <https://doi.org/10.1111/hex.13246>

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>

Dröes, 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>

Georges, J., Diaz-Ponce, A., Lamirel, D., Moradi-Bachiller, S., & Gove, D. (2022). Keeping track of and recognizing the value of Public Involvement work in dementia research. *Frontiers in Neurology*, 13, 1031831. <https://doi.org/10.3389/fneur.2022.1031831>

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). *Ageing & 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>

Masoud S, Glassner A, Patel N, et al. (2021). Engagement with a diverse Stakeholder Advisory Council for research in dementia care. *Res Involv Engagem* 7, 54. <https://doi.org/10.1186/s40900-021-00297-8>

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>

Molinari-Ulate, M., Woodcock, R., Smith, I., van der Roest, H. G., Franco-Martín, M. A., & Craven, M. P. (2022). Insights on conducting digital patient and public involvement in dementia research during the COVID-19 pandemic: Supporting the development of an « E-nabling digital co-production » framework. *Research Involvement and Engagement*, 8(1), 33. <https://doi.org/10.1186/s40900-022-00371-9>

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>

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Murray Alzheimer Research and Education Program (MAREP) and Supporting Inclusion through Intergenerational Partnerships (SIIP)

[Become a research partner](#)

Parkes, J., O'Malley, M., Stamou, V., La Fontaine, J., Oyebode, J. R., & Carter, J. (2022). Lessons learnt from delivering the public and patient involvement forums within a younger onset dementia project. *Dementia (London, England)*, 14713012221110006. <https://doi.org/10.1177/14713012221110006>

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.

Richards, D.P., Birnie, K.A., Eubanks, K. *et al.* (2020) Guidance on authorship with and acknowledgement of patient partners in patient-oriented research. *Res Involv Engagem* 6, 38. <https://doi.org/10.1186/s40900-020-00213-6>

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>

Santana, M.J., Duquette, D., Fairie, P. *et al.* Patient-identified priorities for successful partnerships in patient-oriented research. *Res Involv Engagem* 8, 49 (2022). <https://doi.org/10.1186/s40900-022-00384-4>

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>

Stocker, R., Brittain, K., Spilsbury, K., & Hanratty, B. Patient and public involvement in care home research : Reflections on the how and why of involving patient and public involvement partners in qualitative data analysis and interpretation. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 2021: 24(4). 1349-1356. <https://doi.org/10.1111/hex.13269>

Please send suggestions for additions to this reference list to: Jennifer Bethell Jennifer.bethell@uhn.ca

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>

3) Patient engagement - general

The Alberta SPOR SUPPORT Unit (AbSPORU)	Training Modules
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
Can- SOLVE CKD Network	Training Modules
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:](#)

- 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 (SCPOR)	Onboarding Guide for Patient-Oriented Research Teams – General Information for Researchers.
CIHR - Institute of Musculoskeletal Health and Arthritis	Patient Engagement Resources

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>

Beresford-Dent, J., Sprange, K., Mountain, G., Mason, C., Wright, J., Craig, C., & Birt, L. (2022). Embedding patient and public involvement in dementia research : Reflections from experiences during the « Journeying through Dementia » randomised controlled trial. *Dementia (London, England)*, 14713012221106816. <https://doi.org/10.1177/14713012221106816>

Biddle, M. S. Y., Gibson, A., & Evans, D. (2021). Attitudes and approaches to patient and public involvement across Europe : A systematic review. *Health & Social Care in the Community*, 29(1), 18-27. <https://doi.org/10.1111/hsc.13111>

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>

Fox, G., Fergusson, D. A., Daham, Z., Youssef, M., Foster, M., Poole, E., Sharif, A., Richards, D. P., Hendrick, K., Mendelson, A. A., Macala, K. F., Monfaredi, Z., Montroy, J., Fiest, K. M., Presseau, J., & Lalu, M. M. (2021). Patient engagement in preclinical laboratory research : A scoping review. *EBioMedicine*, 70, 103484. <https://doi.org/10.1016/j.ebiom.2021.103484>

Groothuijse, J.M., van Tol, L.S., Leeuwen, C.C.M. (.Hv. *et al.* Active involvement in scientific research of persons living with dementia and long-term care users: a systematic review of existing methods with a specific focus on good practices, facilitators and barriers of involvement. *BMC Geriatr* 24, 324 (2024). <https://doi.org/10.1186/s12877-024-04877-7>

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>

Kowe A, Panjaitan H, Klein OA, et al. The impact of participatory dementia research on researchers: A systematic review. (2022). *Dementia*. <https://doi.org/10.1177/14713012211067020>

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>

Ocloo, J., Garfield, S., Franklin, B. D., & Dawson, S. (2021). Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety : A systematic review of reviews. *Health Research Policy and Systems*, 19(1), 8. <https://doi.org/10.1186/s12961-020-00644-3>

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>

Teodorowski, P., Jones, E., Tahir, N., Ahmed, S., & Frith, L. (2021). Public involvement and engagement in big data research : Protocol for a scoping review and a systematic review of delivery and effectiveness of strategies for involvement and engagement. *BMJ Open*, 11(8), e050167. <https://doi.org/10.1136/bmjopen-2021-050167>

Yu, R., Hanley, B., Denegri, S., Ahmed, J., & McNally, N. J. (2021). Evaluation of a patient and public involvement training programme for researchers at a large biomedical research centre in the UK. *BMJ Open*, 11(8), e047995. <https://doi.org/10.1136/bmjopen-2020-047995>

4) Patient engagement – approaches to compensation and reimbursement

AbSPORU	Patient Partner Appreciation Guidelines: Compensation in Research
Canadian Institutes of Health Research (CIHR)	Considerations when paying patient partners in research
CIHR Institute of Genetics	Patient Partner Compensation Guidelines

Change Foundation	Should money come into it?
NIHR INVOLVE	Payment and recognition for public involvement
SPOR	Patient Partner Appreciation Policy and Protocol
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>

Richards, D. P., Cobey, K. D., Proulx, L., Dawson, S., de Wit, M., & Toupin-April, K. (2022). Identifying potential barriers and solutions to patient partner compensation (payment) in research. *Research Involvement and Engagement*, 8(1), 7. <https://doi.org/10.1186/s40900-022-00341-1>