

Appendix 1: search strategy for Medline

	Searches
1	((("semi-structured" or semistructured or unstructured or informal or indepth or "in-depth" or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)) or ("focus group*" or qualitative or ethnograph* or fieldwork or "field work" or "key informant" or "grounded theory" or "phenomenol*" or narrative)).ti,ab. or "interviews as topic"/ or "focus groups"/ or narration/ or "qualitative research"/
2	(Dement* or Alzheimer* or Lewy* or FTD or "Frontotemporal degenerat*" or "Frontotemporal disorder*" or "frontal temporal degenerat*" or "frontal temporal disorder*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3	(Need* or Want* or Demand* or Domain* or Importan* or Wellbeing or "Well-being" or "well being" or "Quality of life" or "QoL" or Prefer* or Satisf* or impact* or View* or Outcome* or Hope* or coping or cope* or Expect*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
4	(Experience* or Meaning* or Perception* or Perceiv* or Understand* or subjectiv* or "Everyday li*" or "every day li*" or "every-day li*" or "day-to-day li*" or "day to day li*" or "daily li*" or Narrative* or Perspective* or Scheme* or Exist* or Representation* or Value* or Belief* or Identit* or Self* or selves).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
5	3 or 4
6	1 and 2 and 5

*Planned limits included narrowing data search to studies conducted between 1990 and 2020, and including 'In-Process & Other Non-Indexed Citations' from Medline.

Appendix 2: sources of grey literature to be included

Type of grey literature	Source type	Sources
Dementia strategies & guidelines (international)	Websites	alz.co.uk alzheimer-europe.org nice.org.uk scie.org.uk alzheimer.ca alz.org dementia.org.au
Theses, book chapters, conference proceedings, abstracts and conference papers (international)	Database search	British Library Catalogue (bl.uk)
Organisations of and for people living with dementia and care partners (UK)	Websites	alzheimers.org.uk dementiauk.org youngdementia.uk.org lewybody.org raredementiasupport.org dementiavoices.org.uk Mentalhealth.org.uk Carersuk.org
Organisations of and for people living with dementia (international)	Websites	alz.co.uk alzheimer-europe.org dementiaallianceinternational.org
UK policy and consultations	Websites	gov.uk gov.scot gov.wales northernireland.gov.uk
UK regulators	Websites	Care Quality Commission
UK think tanks focusing on domestic policy	Websites Reports	Centre for Health & the Public Interest Demos Health Foundation Institute for Public Policy Research Involve Joseph Rowntree Foundation The Kings Fund National Centre for Social Research Nesta New Local Government Network Nuffield Council on Bioethics Nuffield Trust

		ResPublica (<i>Care after Cure</i>) Social Market Foundation Wales Institute of Social & Economic Research, Data and Methods (<i>Living well with dementia</i>) The Work Foundation (<i>care partners</i>)
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