

# Dementia Methods Pre-Summit Materials

## Session 1

### Engaging People with Dementia and Their Caregivers in Research

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## I. Introduction

A growing movement internationally has advocated for the active engagement of multiple stakeholders—including patients, caregivers and the larger public/lay community— as a foundational element of patient-centered healthcare decision-making, health policy and health services research. Patient and other stakeholder engagement aims to incorporate active involvement throughout the lifecycle of research, from determining new areas for research to evaluation and dissemination of research results (NIHR 2012). Efforts to include patients or the larger lay community throughout the research lifecycle are grounded in the belief that patient-centered research will better inform more transparent, credible, trustworthy, and ultimately applicable research, clinical and policy decisions (Viswanathan et al. 2004). In the U.S., this view is foundation for “patient-centered outcomes research” (PCOR). Origins of PCOR can be found in community-based participatory research (CBPR) (Viswanathan et al. 2004), although CBPR is often implemented with a more overt advocacy focus.

Engagement of patients or other stakeholders in research can take different forms, along a continuum from consultation to collaboration, and user-led research (NIHR 2012). Consultation refers to engagement practices where patients provide information to sponsors/researchers, generally through use of focus groups or interviews. Collaboration refers to engagement practices inclusive of reciprocal learning and communication from both stakeholders and sponsors/researchers. User-led research is controlled by or directed by users of services (NIHR 2012). Some common engagement activities in these domains:

- Co-researchers, who perform alongside academic researchers and share in decision-making (Collaboration)
- Experts in identification of research needs/questions/priorities (Consultation or Collaboration)
- Advisors in study funding decisions (Consultation)
- Contributors to development of study design/recruitment/conduct based on knowledge of the patient experience in a disease area (Collaboration)
- Liaisons to the larger patient or lay community, especially those hard-to-reach through traditional academic research, to disseminate findings from research studies or champion participation in research studies (Consultation or Collaboration)

## II. National Stakeholder Engagement Policy Mandates

Initiatives in the U.S. and internationally have codified stakeholder engagement as an essential requirement for research initiatives:

In the United Kingdom, stakeholder involvement in research has a long history with the adoption of the National Institute for Health Research (NIHR) INVOLVE initiative in 1996, which serves as a funding and advisory arm for patient engagement activities through the National Health Service. All NIHR funded grants must include a patient or public involvement (PPI) component (Darling & Parra, 2013; NIHR 2017). The James Lind Alliance is a non-profit organization funded by the NIHR Evaluation Trials and Studies Coordinating Centre, established in 2004 to address uncertainties or unanswered questions surrounding effects of treatments that could be addressed through research (JLA, 2016). The Alliance Priority Setting Partnerships (PSP) bring together patients, caregivers and clinicians to produce a Top 10 list of consensus priority unanswered questions in specific health areas (JLA, 2016). The JLA provides a method by which these PSPs should come to consensus (<http://www.jla.nihr.ac.uk/jla-guidebook/>).

The Canadian Institutes of Health Research (CIHR) established the Strategy for Patient-Oriented Research (SPOR) in 2011 to build supportive infrastructure for patient engagement and patient-centered research (Lough 2015; CIHR 2012).

In the United States, the Patient Centered Outcomes Research Institute (PCORI) was established in 2010 with the passage of the Affordable Care Act, to promote the development of research with meaningful input and partnership from patients and other key stakeholders. PCORI-funded research addresses questions and outcomes important to patients and other stakeholders, and funded projects must demonstrate meaningful engagement in the research by patients and/or other stakeholders (Frank 2012).

## III. Identifying Best Practices for Engaging People with Dementia and Their Caregivers

The goal of this document is to synthesize the “lessons learned” from recent reports of research studies or programs in dementia care with a significant patient and/or caregiver engagement component. The focus was on engagement in the research process and not involvement in research as subjects. A literature search of English-language articles in the PUBMED database over the past 5 years was supplemented with a manual search of relevant review-article references identified through the search, and a website review of NIHR-funded programs. All studies in which patients or caregivers of patients with dementia were involved in the design, feedback, evaluation or dissemination of dementia research were selected for review.

The search strategy (Appendix 1) yielded 133 articles. Following abstract review, 23 articles were identified for inclusion. Given the U.K.'s relatively long history of support in people with dementia engagement research, most of the identified studies have been funded by the NIHR, encompassing multiple components of engagement throughout the research process. Below we summarize best practices from the literature, organized by stage at which patients or caregivers collaborated in the research process.

### **Best Practices from Case Studies in People with Dementia Research and/or Caregiver Engagement**

#### ***Research Area Prioritization***

**Alzheimer's Society/James Lind Alliance Dementia Priority-Setting Partnerships (PSP):** In 2012, the Alzheimer's Society Public Health Advisory Committee in collaboration with the University of Cambridge and the NIHR's James Lind Alliance (JLA) completed a year-long dementia priority-setting partnership, with the goal of identifying the Top 10 priorities for dementia research (Kelly et al. 2015). The PSP steering group was tasked with identifying treatment uncertainties from the existing scientific literature, and developing a tool to collect input from the invested clinician, volunteer/caregivers, advocacy, community and research stakeholders (Kelly et al. 2015; Alzheimer's Society U.K. 2013). JLA provided the group chair with support from a scientific expert of the U.K. Database of Uncertainties about the Effects of Treatments. Potential treatment uncertainties were elicited from all stakeholders; the PSP checked each uncertainty against high-quality evidence databases. A list of 146 remaining questions without evidence were prioritized into a Top 10 list during two workshops over the course of one year, with the PSP steering group, a subset of invested stakeholder organizations and a JLA facilitator.

**Carer-Led PPI in Research Planning for Dementia-related Medication Management:** A workshop on Medication Management in dementia, led by caregivers identified through the UK Alzheimer's Society Research Network and the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), explored medication adherence barriers, and experiences of patients with dementia. Caregivers suggested relevant interventions that could be tested, and findings from this workshop served as the framework for a research proposal to improve medication adherence in people with dementia (Poland 2014).

#### ***Study Planning and Implementation***

**National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network (AD PCPRN):** Funded by PCORI, AD PCPRN is a collaborative registry maintained by the Mayo Clinic, University of Florida, Brain Health Registry, and USAgainstAlzheimer's. The registry aims to include subjects underrepresented in clinical trial research, and will include phenotypic markers, baseline and longitudinal cognitive testing for use in research and recruitment (Petersen 2016).

**DeNDRoN Focus Groups to Solve Trial Recruitment Challenges:** The U.K.-based DeNDRoN, comprised of patients with dementia, caregivers, representatives from nonprofit research, and advocacy groups, and research experts were asked to assist with solutions to overcome problematic low recruitment for an Alzheimer's drug trial (DOMINO-AD). A set of focus groups targeting patients and caregivers were moderated to determine potential barriers to recruitment and ways to improve the research study experience for caregivers. Solutions raised by the groups included increasing study promotion and interaction with primary care practitioners to facilitate referrals into the study. Authors noted a surge in recruitment following implementation of ideas from the focus groups (Iliffe 2011).

**DeNDRoN and the MUSTARD-PD Drug Trial – Using Patient-Sensitive and Appropriate Language in Study Materials:** Lay researchers on the steering committee of the MUSTARD-PD trial (evaluating donepezil in Parkinson's Disease dementia) provided focused feedback that the language used to introduce the idea of dementia in patient brochures was potentially insensitive and inappropriate. DeNDRoN, in concert with patient and lay input, developed a revised patient information sheet reflective of more sympathetic wording, using the signs/symptoms of dementia rather than the word 'dementia' itself (Iliffe 2011).

**DeNDRoN and the RESULT Study – Including Patients and Caregivers in Design and Evaluation of Observational Studies:** RESULT is a U.K.-based health resource utilization study among patients with motor neurone disease, Huntington's disease, multiple system atrophy, dominantly inherited ataxias, progressive supranuclear palsy, post-polio syndrome, and Charcot-Marie tooth disease. DeNDRoN formed a panel of patients, caregivers and lay individuals to oversee the conduct of the study, with input in design, medical record review and modeling activities. A questionnaire developed by the panel allowed the public to review study outcomes, dissemination plans and implementation strategies with the final result of a roadmap for additional studies to be undertaken (Iliffe 2011).

**Co-Researchers who Serve as Study Interviewers:** A Birmingham, U.K. based study in which people with dementia served as co-researchers, providing patient experience and context to a study interviewing people with dementia on care transitions. Co-researchers were additionally trained, generally in their homes, to conduct interviews with dementia research study participants. A set of memory aids and interview guides were developed to assist with memory and flow of interviews. Authors report significant effort devoted to maintaining relationships between researchers and co-researchers for a successful study. Benefits noted include co-researchers providing study participants with authenticity, honesty and experiential value. Benefits for co-researchers were practicing communication skills and using cognitive abilities (Tanner 2012).

**Telehealth Support Group for Spouses of People with Atypical Dementias:** At the Canadian Rural and Remote Memory Clinic in Canada, spouses of patients with atypical dementias were involved in development of a telehealth support group, specifically in intervention design, data collection, interpretation, and dissemination of results. Authors report increased capacity building and sustainability of the program as benefits of the collaborative approach (Morgan 2014).

### ***Identifying Relevant Outcomes***

**Partnering with Patients to Co-analyze Themes from Interview Research:** Northern Ireland's Alzheimer's Society Service User Review Panels are comprised of people with dementia who regularly discuss topics relevant to the Alzheimer's Society. This panel partnered with researchers to summarize and extract themes from previously performed anonymized interviews with people with dementia. Expansion of the insights and practical perspectives used to interpret interview responses led to ideas for lay dissemination of results (Stevenson 2017).

**Improving Interpretation and Understanding of Research:** At the Rural and Remote Memory Clinic, a program for early assessment and diagnosis of dementia has benefitted from patient feedback through survey response and evaluation of clinic operations. This feedback has informed changes to the program (Morgan 2014).

**Culturally Appropriate Cognitive Assessment Measures:** To derive cognitive measures appropriate to the Aboriginal population in Saskatchewan, a series of focus groups was conducted with Aboriginal grandmother caregivers. A collaborative process of thematic analysis between the grandmothers and research team led to modifications in existing screening tools and neuropsychological testing protocols culturally appropriate for the Aboriginal population (Morgan 2014).

## **IV. Conclusions and Future Steps for Patient/Caregiver Involvement in Research**

The literature on patient engagement continues to grow. Approaches to patient and caregiver engagement vary in terms of level, duration and extent of involvement. Adoption of engagement in research has also traditionally been hampered by a lack of evaluation (Wilson 2015). Only one study examined here referenced any measure of post-engagement evaluation (Illife 2011). Determining, then, which engagement approaches should be prioritized for replication or adaption remains a challenge.

An evaluation report from the NIHR-funded RAPPOR study examined peer-reviewed and gray literature and interviews with researchers who used PPI in their work, to evaluate the different approaches to PPI, in dementia and other conditions (Wilson 2015). In their final report, the authors summarize six required actions for positive outcomes and impact of PPI in future research studies:

1. Researchers and lay representatives have a shared understanding of the moral and methodological purpose of PPI
2. A key individual who serves as PPI-coordinator

3. Lay representatives have a strong connection with the target study population,
4. The whole research team being positive about PPI input and fully engaged with it,
5. Efforts to develop relationships established and maintained over time, and
6. PPI is evaluated in a proactive and systematic approach.

For research studies with less developed infrastructure or those requiring only intermittent PPI, the authors recommend including representatives who could act as a link to broader constituencies. For studies without the infrastructure or resources to include systematic PPI, researchers should focus on developing capacity and building relationships with lay representatives as a first step (Wilson 2015). These guidelines map onto the conceptual model of PCOR expressed by PCORI, with foundational elements and actions required to achieve outcomes goals, against a backdrop of principles of trust, transparency, bi-directional learning, honesty, reciprocal relationships, partnerships, and trust (see Forsythe 2017).

## V. Implications for Research Agenda

It is noteworthy that 67 of the 146 initial research questions identified through the James Lind Alliance process relate to care and services for dementia (Alzheimer's Society 2013). This list is a fruitful one for identifying specific methods questions that must be addressed to enable further research.

Questions relating to care and services that suggest methods dilemmas for further consideration as part of a methods research agenda are presented in **Appendix 3**.

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## Appendix 1. Literature Review Search String

Search (((((((("Patient Participation"[Mesh] OR "Consumer Participation"[Mesh] OR "patient input"[tw] OR "patient collaboration"[tw] OR "engaging patients"[tw] OR "engages patients"[tw] OR "engaged patients"[tw] OR "patient partner"[tw] OR "patient partnership"[tw] OR "patient partners"[tw] OR "patient participation"[tw] OR "stakeholder participation"[tw] OR "stakeholder collaboration"[tw] OR "engages stakeholders"[tw] OR "engage stakeholders"[tw] OR "engaged stakeholders"[tw] OR "engaging stakeholders"[tw] OR "stakeholder partnership"[tw] OR "stakeholder partners"[tw] OR "consumer participation"[tw] OR "community participation"[tw] OR "public participation"[tw] OR "patient engagement"[tw] OR "stakeholder engagement"[tw] OR "consumer engagement"[tw] OR "community engagement"[tw] OR "public engagement"[tw] OR "patient involvement"[tw] OR "stakeholder involvement"[tw] OR "consumer involvement"[tw] OR "community involvement"[tw] OR "public involvement"[tw] OR "public partners"[tw] OR "public partner"[tw] OR "public partnership"[tw] OR "lay participation"[tw] OR "lay engagement"[tw] OR "lay involvement"[tw] OR "engaging community"[tw] OR "engaged community"[tw] OR "engaging communities"[tw] OR "engages communities"[tw] OR "engaged communities"[tw] OR "community partner"[tw] OR "community partnership"[tw] OR "community partners"[tw] OR "payer engagement"[tw] OR "payer involvement"[tw] OR "insurance participation"[tw] OR "employer involvement"[tw] OR "employer participation"[tw] OR "employer engagement"[tw] OR "pharmaceutical involvement"[tw] OR "engaging caregivers"[tw] OR "engaged caregivers"[tw] OR "caregiver engagement"[tw] OR "caregiver involvement"[tw] OR "caregiver participation"[tw] OR "caregiver partner"[tw] OR "carer engagement"[tw] OR "engaged carer"[TW] OR "engaged carers"[TW] OR "engages carers"[TW] OR "care giver engagement"[tw] OR "care giver involvement"[tw] OR "care giver partner"[tw] OR "study partner"[tw] OR "engaging carers"[TW] OR "carer engagement"[TW] OR "carer participation"[TW] OR "carer collaboration"[TW] OR "consumer collaboration"[tw] OR "engaging consumers"[tw] OR "engaged consumers"[tw] OR "consumer partnership"[tw] OR "provider engagement"[tw] OR "provider participation"[tw] OR "provider involvement"[tw] OR "clinician engagement"[tw] OR "clinician involvement"[tw] OR "clinician participation"[tw] OR "engaged research"[tw] OR "engagement research"[tw] OR "research engagement"[tw] OR "engagement framework"[tw] OR "facilitating engagement"[tw] OR "Patient and public involvement"[tw] OR "PPI"[tw] OR "partnered research"[tw] OR "participatory research"[tw] OR "co-research"[tw]) AND (Dementia[Mesh] OR Alzheimer Disease[Mesh] OR "Dementia"[Text Word] OR "Dementias"[Text Word] OR "Alzheimer"[TW] OR "Alzheimers" [TW] OR "Alzheimer's"[TW]) AND ("Patient"[tw] OR "Caregiver"[tw] OR "care giver"[tw] OR "caregivers"[tw] OR "carer"[tw] OR "carers"[tw] OR "study partner"[tw] OR "study partners"[tw] OR "family care"[tw]) AND English[lang]))) AND "last 5 years"[PDat]))) AND "last 5 years"[PDat])) Filters: published in the last 5 years

## Appendix 2. Inclusion Criteria for Search Results

Inclusion	Exclusion
Patient population diagnosed with dementia, dementia symptoms, or pre-dementia	Non-English language
CBPR where community members (participants and carers) are consulted in research, or intervention methods, or interventions and observational research focused on improving support for patients, or carers, OR Non-review articles summarizing best practices, lessons learned, patient/carer experience/involvement centered interventions	Non-peer reviewed
Public/patient/caregiver (PPI) input into some aspect into the research process - recruitment, design, conduct, or dissemination	Review/ Meta analyses
Publication year: 2012-2017	Not relevant to dementia or not inclusive of patient/public involvement in research process

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### Appendix 3. James Lind Alliance Dementia PSP Questions Related to Care and Services for Dementia (Alzheimer's Society 2013)

#### Question

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6 Does high quality care from carers/care staff improve outcomes for people with dementia? What are effective ways to implement such high quality care in all settings including care homes and hospital?

Including:

- care that considers person-centered care, behavioral care interventions and kind, respectful and dignified caring
- effect on quality of life, behaviors that challenge and progression of the disease

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7 What individual characteristics of care staff predict the ability to provide high quality/person-centered care for dementia?

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8 Are specialist care homes/facilities/nurses for people with dementia more effective at maintaining quality of life/quality of care for people with dementia at all stages of the disease compared to non-specialist generic care?

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#### Care in different settings – acute/hospital care

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9 What is the best way to care for people with dementia when they have acute health care needs?

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10 Would a coordinated, specialist unit within an acute hospital, instead of admission to usual acute hospital ward for people with dementia affect length of stay, the experience and outcomes for the person with dementia, progression of the disease, cost and use of ambulance service?

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#### Care in different settings – home/community care

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11 How does the input of day-to-day paid care and support (during the day and/or at night) compared to care from family/carers alone affect outcomes for people with dementia living at home? How does this impact on carers?

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12 How effective is training for carers/family members on improving quality of care, quality of life, ability to stay in own home for people with dementia and outcomes for carers?

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13 How does home care (with or without the input of additional professional care) compare to care homes for outcomes for people with dementia at all stages of the disease?

In terms of:

- quality of life
- behavior
- physical function
- progression of the disease
- costs

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14 What are the most effective (and cost effective) ways of supporting people with dementia living at home and their carers, including during and after the diagnosis process?

Including:

- the specific type of help that is effective e.g. information, transport, telecare
- how health and social care services and other agencies can best be coordinated
- how access to support and services can be improved, e.g. one point of contact
- the effect on delaying admission to care homes
- people with dementia who live alone
- people with dementia who are carers for someone else

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15 Is regular attendance at day centres with activities and social interaction effective at improving outcomes for people with dementia and carers, including quality of life and ability to live at home for longer?

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16 How effective are models of housing and care used in countries other than the U.K. in supporting care in the community for people with dementia?

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17 How does the input of day-to-day professional care (during the day and/or at night) compared to care from family/carers alone affect outcomes for people with dementia living at home? How does this impact on carers?

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18 How effective would easier access to short-break or respite care (at home or in other settings) be in reducing stress and maintaining quality of life for carers of people with dementia? How can respite care best be organized to support both the person with dementia and the carer?

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- 19 How effective are different models of housing with care (integrated/separated/specialist/dedicated/hybrid) for supporting people living with dementia on quality of life/outcomes/costs of people with dementia and their carers? How do these compare to residential care?

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### Care – general

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- 20 What is the best way to care for people with advanced dementia (with or without co-morbidities) at the end of life?
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- 21 What are the best ways to care for people from ethnic minority groups with dementia in all care settings?
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- 22 How can the best and most cost-effective ways to care for people with dementia, including research findings, be most effectively disseminated and implemented into care practice in all care settings?
- 
- 23 What are the most effective methods to improve the awareness and attitudes of all health and social care professionals towards people with dementia in all settings and improve their understanding of the challenges faced by carers and families?
- 
- 24 What interventions/techniques/facilities/staff training are of most benefit in improving the quality of life for people with dementia and their carers in all settings and at all stages of the disease?
- 
- 25 What are the most effective management approaches and models of care for people with concurrent dementia and vision problems/sight loss in all settings and at all stages of the disease?
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- 26 What are the most effective management approaches and models of care, including equipment, for people with concurrent dementia and hearing loss in all settings?
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- 27 Does intervention to correct vision problems/sight loss in people with dementia improve symptoms including quality of life?

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### Care planning

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- 30 Is advanced care planning for both the person with dementia and carers effective for outcomes for the person with dementia (including quality of life and acute events), and for good end of life care that meets the previously expressed wishes of the person with dementia?

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## Managing behavior

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- 66 Is 'reality orientation' (as a specific therapy) effective for the management of behavior in dementia?
- 
- 67 What pharmacological and/or non-pharmacological interventions (or combinations) are most effective (for people with dementia and carers) for managing challenging behaviour/neuropsychological symptoms in dementia?
- 
- 68 Is sedation at night for people with dementia (to allow carers to sleep) effective and what is the effect on behavior, quality of life during the day, and time to move to a care home?
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- 69 What are effective ways to care for people with dementia who are in denial about their condition (care, medical and legal routes)?
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- 70 Why do people with dementia have cognitively 'good' and 'bad' days, or moments? Could this information be used to identify effective interventions or be used to improve behavioral management?

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## Managing behavior (continued)

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- 71 What are the most effective methods to manage sleep disorders and sleep patterns in people with dementia?
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- 72 What are the most effective ways to manage 'wandering' or walking in people with dementia?
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- 73 What are the most effective ways to manage 'sundowning' (becoming more agitated and confused in the late afternoon and early evening) in people with dementia?
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- 74 How effective is a regular routine and consistent environment for managing symptoms/behavior/outcomes for people with dementia, compared to a less stable and consistent environment (for example, should the person with dementia be stimulated by changes, e.g. holidays and changes of scenery)?

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## Management of physical conditions

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- 75 How can urinary tract infections be prevented in people with dementia and what is the effect of urinary tract infections on the symptoms and progression of dementia?
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- 76 What are the best ways to manage incontinence in people with dementia?

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## Medication – effectiveness of current treatments

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- 79 Is combined treatment of dementia with cognitive stimulation and acetylcholinesterase inhibitors clinically effective and cost-effective, (compared to either treatment on its own) in terms of cognition, global functioning, daily living activities and quality of life?
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- 80 Are acetylcholinesterase inhibitors (donepezil, galantamine, rivastigmine) or memantine effective and cost-effective for people with dementia (and its sub-types)?
- In terms of:
- improving quality of life
  - reducing non cognitive symptoms (including challenging behavior)
  - when used long term (more than six months)
  - for slowing progression of dementia
  - in treatment of severe dementia
  - compared to non-pharmacological therapies
  - which are most effective when compared to each other?
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- 81 Are any combinations of acetylcholinesterase inhibitors, and/or memantine, or switching from one drug to another more effective for treatment of dementia, than a single drug at all stages of the disease in managing symptoms/slowing progression of dementia?
- 
- 82 What are the characteristics of people with dementia (including those with a family history/genetic markers) for whom current treatments are effective (compared to ineffective), or who suffer side-effects (compared to those who do not suffer side-effects)? Can treatment be optimized by linking to individual profiles?
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83 Is it possible to say if there is a stage of dementia when it is the optimum time to stop prescribing acetylcholinesterase inhibitors or memantine?

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84 What are the most effective ways of treating and caring for people in the advanced stages of dementia, when they are no longer responding to acetylcholinesterase inhibitors, or memantine?

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### Medication (general)

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85 Can the prescription of all types of medication for people with dementia be reduced by improving quality of care/meeting care needs of people with dementia more fully?

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86 Are there any drugs/medications that are effective in preventing/delaying the onset of dementia? Are they also effective in those with a family history or genetic risk factors for dementia?

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87 Is aspirin effective for the prevention or treatment of dementia? What dose is effective?

Including:

- those with mild cognitive impairment (MCI)
- those with normal cognition but with evidence of early disease pathology
- those with a family history/genetic risk factors for dementia?

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88 Can statins prevent/delay onset of dementia when therapy is started in mid-life? Are they effective for those with a family history/genetic risk factors for dementia?

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89 Does long-term use of any drugs/medications or combinations of drugs (including recreational drugs) for other health conditions increase risk of dementia?

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90 Is there a link between drugs used to treat anxiety/depression/mental health conditions (e.g. benzodiazepines such as diazepam (valium) or anti-depressants) and risk of dementia?

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91 How effective are medicines designed for other illnesses for the treatment of dementia (e.g. treatments for Parkinson's disease)?

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92 Is there any interaction between drugs used to treat dementia and other commonly prescribed drugs for co-morbidities (e.g. diabetes, hypertension, thyroid problems, Parkinson's disease), including at all stages of the disease?

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93 How can the side-effects of drug treatment for dementia be minimized?

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94 What is the impact of anesthesia on subsequent outcomes/progression of the disease in people with dementia?

### Mental health/psychological therapies

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95 What are the most effective treatments for depression and/or anxiety in dementia and can the effective treatment of depression/anxiety improve outcomes in people with dementia, including slowing cognitive decline and progression of the disease?

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97 Are counseling or other psychological therapies effective to prevent/delay the onset of dementia, or to treat and manage dementia? At what stage of life do these need to start to be effective? How can access to these therapies be improved?

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98 What coping strategies are effective for people with dementia to deal with cognitive decline/memory failure?

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116 Are strategies to prevent physical trauma (brain/head injury) effective for the prevention of dementia, including in those with a family history/genetic risk factors for dementia?

### Treatment and care therapies

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129 What is the impact of a diet/nutrition intervention for people with dementia on prevention of dementia-related malnutrition and weight loss, dementia symptoms and the progression of the disease?

Including:

- in all sub-types of dementia
  - for end-of life care
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132 Is physical activity (including outdoor exercise) effective in the treatment and care of dementia, including effect on behavioral, physical, psychological symptoms, quality of life and progression of the disease?

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133 Are 'brain games' and other cognitive stimulation or learning processes effective for the management of dementia (e.g. slowing cognitive decline and the progression of the disease, managing behavior, anxiety and agitation, maintaining quality of life)?

Including:

- the types of cognitive stimulation that are effective
- which are effective in different settings e.g. at home or in care homes
- effectiveness compared to general activity/social groups
- the most effective mode of delivery e.g. one to one/groups/individually tailored.

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134 Is social interaction effective in maintaining quality of life and slowing progression of the disease in people with dementia (and maintaining quality of life of carers)?

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135 Are non-pharmacological (not drug) or alternative therapies effective (and cost-effective) for the treatment and management of dementia?

Including:

- for different sub-types of dementia (e.g. vascular dementia, Lewy body dementia)
- the effectiveness in different settings (e.g. at home/care homes)
- which therapies are most effective
- the effectiveness of including carers (family/home carers or care staff) in treatment programs
- the effectiveness for preventing and managing behaviors that challenge others

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136 Is music (e.g. singing, playing recordings, playing instruments) effective in helping to improve symptoms of dementia, including quality of life?

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137 What is the effect of reminiscence therapy/life story work on outcomes in dementia, including quality of life?

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138 Are activities for people with dementia (including outdoor activities, art therapy) effective in management of mood, behavior, anxiety, and agitation in people with dementia and can they reduce the need for psychoactive drugs in people with dementia?

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139 Is occupational therapy effective for the management of dementia (including cognition, behavior and quality of life) in all settings?

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- 140 Is physiotherapy effective for the management/improvement of physical functioning/delaying progression of the disease for people with dementia (all sub-types) in all settings?
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- 141 Is (amyloid) vaccination therapy effective for the treatment of dementia?
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- 142 Are stem cells effective for the prevention or treatment of dementia?  
Including:
- in people with family history/genetic risk factors for dementia
  - for different sub-types of dementia
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- 143 Can systematic investigation to look for co-morbidities in people with dementia and appropriate treatment for co-morbidities lead to better outcomes for dementia? What are optimum ways to treat and care for people with co-morbidities and dementia?
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