Outcomes of the James Lind Alliance Dementia priority setting partnership

Steering group

We are grateful to representatives from the following organisations for their contributions to the James Lind Alliance Dementia priority setting partnership.

Dear colleagues

Welcome to the James Lind Alliance priorities for dementia research.

Alzheimer's Society is committed to ensuring that research funding is used as effectively as possible to alleviate the impact and burden of dementia and to improve the quality of life for people affected by the condition. It was for this reason that Alzheimer's Society commissioned Professor Carol Brayne from the Institute of Public Health at the University of Cambridge to lead this exercise to select priorities related to the treatment, diagnosis, prevention and care in dementia, so that future funding may be targeted to the areas of highest need.

The prioritisation process has produced a number of outcomes that we would now like to see taken forward. While these will not be used directly as priorities for Alzheimer's Society's Research funding, we hope that these questions will be addressed in the wider research field.

The headline of these is a top 10 list of priorities for dementia research, but underneath this is a wealth of further research questions that might be addressed. Importantly this exercise involved matching priorities against the current evidence, allowing us to show where the priorities reflect genuine gaps in evidence.

These priorities represent the collective view from a wide range of stakeholders representing people affected by dementia, practitioners and clinician groups. We now see it as the role of all those interested in dementia research to consider these priorities and the contribution that they can make to advance our knowledge of quality of life in dementia.

Dementia represents a great unmet need and research is required on all fronts. Developing priorities for biomedical research covering the causes and mechanisms of dementia was deliberately not included in the scope of this exercise, but remains of high importance.

We hope that you find the research priorities outlined here of interest and agree with their importance.

With very best wishes

Dr Doug Brown
Director of Research and Development

Contents

The need for research priorities

After being relatively neglected for many years, dementia is beginning to be recognised as a high priority on the political and social agenda. The new urgency is welcomed, since dementia poses one of the greatest health and social challenges to both developed and developing nations in the 21st century.

In the UK, the Prime Minister has committed to a dementia challenge that will seek to improve detection of dementia, develop communities that are dementia friendly, following the G8 Summit on dementia, has committed to increase government funding to over £130 million by 2025.

Despite the increased investment, dementia research is still underfunded in comparison to other diseases. It is therefore important to prioritise the new funding so that it seeks to answer questions that will have the most impact for people affected by dementia.

Building on this need to ensure funding is targeted effectively, Alzheimer's Society initiated a priority-setting partnership in collaboration with the James Lind Alliance and experts in public health. The priority setting partnership sought to bring together a wide range of organisations representing the views of people affected by dementia, practitioners and clinicians to collectively agree on priorities addressing the care, treatment, diagnosis and prevention of dementia.

The result of this exercise has been to produce a top 10 list of priorities that are considered to be of high importance for research. In light of increased funding, these priorities are extremely timely, and offer a framework for all interested in dementia research and care to consider how directly to improve the quality of life for people affected by dementia.

Alzheimer's Society involves people affected by dementia in our Research funding programme, and so these priorities will be different. It is hoped that the priorities here will help guide funders to identify gaps in the knowledge and guide research funding.

Top 10 priorities for dementia research

The following questions were prioritised by people with dementia, carers, and health and social care professionals to inform the future of dementia research. The priorities were launched at Alzheimer's Society's Research conference on 27 June 2013.

The final top 10 priorities

1   **What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?**

2   **How can the best ways to care for people with dementia, including results from research findings, be effectively disseminated and implemented into care practice?**

3   **What is the impact of an early diagnosis of dementia and how can primary care support a more effective route to diagnosis?**
Particular questions were raised about the impact of early diagnosis on:
- Health-related outcomes for people with dementia and their carers (including impact on the progression of the disease and life expectancy, mental health, quality of life, attitudes of healthcare professionals to treatment for people with dementia, and on outcomes for carers, including quality of life and mental health).
- Wider outcomes in society for people with dementia and carers/family (including financial planning, insurance issues, employment prospects, independence, access to other healthcare services, driving).
- Health and social care services.

Particular questions about more effective routes to diagnosis in primary care included:
- Routes to faster referral to specialists, where appropriate.
- The best way to communicate a diagnosis of dementia, including who is the best person to communicate the diagnosis and where it should be delivered; how best to involve relatives and carers taking confidentiality into account.
- The psychological impact of a diagnosis of dementia on the person and carers.

4   **What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with dementia?**
This question included alternatives to anti-psychotic drugs; activities and stimulation; person-centred and behavioural care techniques; which therapies are most effective in different care settings; the effectiveness of involving carers (family/home carers or care staff); effectiveness for different sub-types of dementia.

5 **What is the best way to care for people with dementia in a hospital setting when they have acute health care needs?**

This question included uncertainties about the effectiveness of a coordinated, specialist unit for people with dementia within an acute hospital, instead of admission to usual hospital acute ward and the impact on length of stay, the experience and outcomes for the person with dementia, progression of the disease, cost-effectiveness and use of the ambulance service (potential to reduce transfers between wards/hospitals).

6 **What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake?**

This question included the role of professional and lay carers; whether assistance with feeding/drinking improves other outcomes e.g. weight, physical functioning, behavioural symptoms, progression of the disease; effectiveness of food supplements and any adverse effects of food supplements; potential role of a trained hydration team in hospitals and other care settings; role of speech therapy in improving/maintaining swallowing and chewing reflex.

7 **What are the most effective ways of supporting carers of people with dementia living at home?**

Particular questions were raised about:

- The specific type of help that is effective, including questions about support from paid carers, consistency of paid care, help during the night, specialist care provider service for home care, fast support response, training for family carers, day care centres, respite care, provision of information, help with paperwork, transport, telephone help lines.

- How health and social care services can best be coordinated and accessed including to improve speed of access to support, one point of contact rather than several agencies, improved communication between services.

- Outcomes asked about were: the factors that enable people with dementia to stay at home as long as possible and delay institutionalisation, maintain quality of life for people with dementia and carers, maintain physical and mental health for carers.

8 **What is the best way to care for people with advanced dementia (with or without other illnesses) at the end of life?**

This question included references to alternatives to withdrawing food and drink.

9 **When is the optimal time to move a person with dementia into a care home setting and how can the standard of care be improved?**

Particular questions included whether it is better to move a person with dementia to a care home at an earlier or later stage of the disease for outcomes including quality of life, trauma to the person with dementia, behaviour, physical function, costs; consideration of conditions for staff (salaries, career structure and training) in improving care; monitoring of standards of care, characteristics of a good care home.

10 **What are the most effective design features for producing dementia friendly environments at both the housing and neighbourhood levels?**

This question included the consideration of design/adaptation of housing e.g. signage, scenery, space & light; for different cultural and ethnic minority groups; design features that best support and enable people with dementia and carers to maintain quality of life, manage symptoms, minimise behavioural problems, slow progression of the illness and allow people to stay in their own homes for longer?

Process for setting priorities

Building the partnership

Alzheimer's Society initiated the Dementia priority setting partnership with the James Lind Alliance in November 2011 to identify the priorities for dementia research. The project covered research into the prevention, diagnosis, treatment and care of dementia.

The whole project was initiated by the Public Health Advisory Committee of Alzheimer's Society and a team from the University of Cambridge. NIHR CLAHRC (collaborations for Leadership in Applied Health Research) for Cambridgeshire and Peterborough and Alzheimer's Society carried out the survey and analysis supported by the steering group.

James Lind Alliance (JLA)
The James Lind Alliance is a non-profit making initiative that brings together patients, carers and clinicians to identify the priorities for research for a particular health condition. It was established in 2004 after the realisation that what researchers want to research can be very different from what patients and clinicians want researched. The JLA has developed excellence in the process and provide an impartial overview and structure to guide partnerships. It aims to ensure that the process is fair and free from bias, and ensure patients, carers and clinicians have an equal voice.

To date, the JLA has successfully completed 16 partnerships which have initiated considerable interest and publicity and, as a result, research has been funded to begin to address the priorities. There are a number of ways to set priorities for research, but Alzheimer's Society decided that the JLA methodology was rigorous and well-researched with clear, proven and positive outcomes. Working with the JLA has been a great success and a very positive experience.

Steering group
A steering group was convened to coordinate and oversee the project, consisting of 13 members representing people with dementia and their carers, health and social care professionals and researchers.

The steering group consisted of:
- Nicola Hart, Alzheimer's Society
- Claire King, Alzheimer's Society Research Network volunteer
- Denise Wilson, NIHR Dementia & Neurodegenerative Diseases Research Network (DeNDRoN)
- Graham Stokes, Bupa
- Carol Brayne, University of Cambridge
- Louise LaFortune, University of Cambridge
- Sarah Kelly, University of Cambridge
- Angelique Mavrodaris, University of Warwick
- Jill Manthorpe, King's College London
- Tony Bayer, Cardiff University
- Claire Lawton, Cambridge and Peterborough NHS Foundation Trust.

The group was chaired by Katherine Cowan from the James Lind Alliance and was supported by Mark Fenton, Editor of UK DUETs (UK Database of Uncertainties about the Effects of Treatments).

Partner organisations

Organisations and representatives who can advocate for people with dementia and their carers and health and social care professionals were invited to take part in the process. Following an introductory meeting on 11 April 2012, there was great enthusiasm for the project, and a wide range of organisations signed up as partners to the project.

Partner organisations have played an instrumental role in promoting the survey to collect the questions that people want to see answered through research into the areas covered by this project and prioritising those that are the most important.

Identifying the questions

Survey

A survey was designed through consultation with stakeholder groups to collect people's questions on the prevention, diagnosis, treatment and care of dementia. The survey was distributed in print and online, and was launched on 1 April 2012. It was open for three months.

Alzheimer's Society, together with steering group members and partner organisations, distributed the survey to their members and contacts, including people with dementia and their carer, health and social care professionals, and members of the public. Over 4,000 questions were collected from the survey respondents.

Demographic data from the respondents was analysed to ensure that, as far as possible, the responses were representative of the whole community. Questions were submitted from a range of people of various ages and backgrounds. Health and social care professionals, members of the public with no experience of dementia and people from Black and Minority Ethnic groups were particularly challenging groups to access, and several extra steps were taken to specifically target these groups.

Collating the results

Alzheimer's Society awarded a grant to the University of Cambridge to sort through the data and the steering group supported this. Each question was checked against up-to-date systematic reviews to ensure it could not already be answered by high quality robust evidence. Only a very small number of questions were identified as known questions and removed from the list. Duplicate questions or those covering similar topics were combined and, where necessary, questions were re-formatted to represent research questions. Any questions that were out of the scope of the survey (treatment, diagnosis and care of dementia) were excluded.

This significantly reduced the number of questions, however further short listing was required to reduce the l ist to a manageable size for prioritisation. The steering group made the decision to remove questions that were only submitted by one or two people. These questions were reviewed by the steering group and Alzheimer's Society's Helpline staff, who re-entered any that they felt were common enquiries.

Sorting through the questions was a huge task that took several months to complete. Once the process of sorting through the data was complete, 146 questions were remaining. These are listed in Appendix A.

All questions that could not be answered by up-to-date evidence will be published on NHS Evidence in the UK Database of Uncertainties about the Effects of Treatment (UK DUETs) at **www.library.nhs.uk/duets** The questions that were removed will also be on DUETS to ensure no information is lost.

Prioritising the questions

The long list of questions was sent out to partner organisations at the beginning of May 2013, to rank their top 10 priorities. Each partner organisation was able to submit one vote. To do this, many organisations consulted with their members and colleagues. For example, Alzheimer's Society's vote was formed through consultation with the Research Network, a group of 250 people people with dementia, carers and former carers. Thirty-six organisations participated, representing the views of people with dementia and their carers and representing the views of health and social care professionals.

The votes were collated bringing together separate totals for people with dementia and their carers, and health and social care professionals. The top 25 questions that were ranked the highest priority were taken as a shortlist through to the final workshop where the top 10 were decided.

Deciding the top 10 questions

Partner organisations were invited to send a representative to a workshop on 12 June 2013, to contribute to deciding the top 10 questions. The workshop was attended by people with dementia and their carers, and health and social care professionals. There were 18 attendees in total.

Participants were sent the short list of questions in advance to think about their priorities and familiarise themselves with the questions to aid discussion. The workshop, which was chaired by the JLA, used Nominal Group Technique, a method involving a number of small group sessions and ranking exercises. Each participant was given the opportunity to express their views on which questions they thought should be prioritised and to hear other people's perspectives.

After a long day of lengthy discussions, debates and compromise, the top 10 questions for dementia research were agreed through consensus.

Participants from the workshop said:

'I learnt a great deal from the people I met at the event and I really appreciated the opportunity to express my views. I was very pleased with the priorities that were agreed at the meeting.'

'Carers often feel so isolated, but this was a chance to put our hard-won expertise to use for the benefit of others – so thank you for the opportunity to do this, I think we all had our horizons widened.'

Next steps

With commitments made by the government to increase funding in dementia research, these research questions – that have been prioritised by people who are affected by dementia – are extremely timely.

Alzheimer's Society will work with the steering group, partner organisations and funding bodies to ensure that these questions are appropriately addressed by the wider research community.

If you are interested in taking any of the priorities forward, or you would like more information, please contact the Alzheimer's Society at **research@alzheimers.org.uk**

Appendix A – The list of questions covering the prevention, diagnosis, treatment and care of dementia

Below is the list of research questions that was sent to partner organisations in May 2013. Each organisation was asked to work with their colleagues and members to rank the top 10 questions that they would like to see prioritised for research.

Question

Care in different settings – care homes

1. Is there any impact on the quality of life and quality of care of people with dementia when care is provided for profit compared to not-for-profit?

2. What are the characteristics of a good care home for people with dementia (including consideration of barriers to care) and how can standards of care in care homes be improved and monitored?

3. Are people with dementia better cared for in care homes/mental health units with other people with dementia or with people who do not have dementia in terms of progression of the disease and quality of life?

4. Is it better for people with dementia to move to care homes at an earlier or later stage of the progression of the disease in terms of outcomes/trauma to the person?

5. Do improved conditions (eg salaries, career structure and training) for care staff improve quality of care/quality of life for people with dementia?

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-centred care, behavioural care interventions and kind, respectful and dignified caring
   - effect on quality of life, behaviours that challenge and progression of the disease.

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

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?

Care in different settings – acute/hospital care

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

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?

Care in different settings – home/community care

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?

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?

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
- behaviour
- physical function
- progression of the disease
- costs.

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 eg 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, eg 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.

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?

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

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?

Care in different settings – home/community care (continued)

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 organised to support both the person with dementia and the carer?

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?

Care – general

20 What is the best way to care for people with advanced dementia (with or without co-morbidities) at the end of life?

21 What are the best ways to care for people from ethnic minority groups with dementia in all care settings?

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?

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?

27 Does intervention to correct vision problems/sight loss in people with dementia improve symptoms including quality of life?

Care planning

28 What do services need in terms of education, information and resources to ensure people who have dementia are actively involved in all aspects of their care and planning?

29 What are typical timescales for progression of each stage of all types of dementia and what are the typical characteristics and care needs at each stage to allow better planning for carers and people with dementia?

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?

Carers

31 Do carers of people with dementia have a greater risk of developing dementia?

32 What is the impact of long term care for a person with dementia at home on the life of the carer/family?
Including:
- quality of life
- physical and mental health
- finances
- morbidity/mortality.

33 What practical and psychological interventions are effective for carers to help people with dementia?

34 Does currently available treatment (including pharmacological and other treatments) for people with dementia improve mental health and quality of life in their carers (by improving attitude and mood in the person with dementia)?

35 Is psychological therapy effective in reducing stress and improving quality of life of carers of people with dementia?

36 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?

Communication

37 What techniques are effective to allow health and social care professionals to communicate most effectively with people with dementia and what is the effect on other outcomes eg, agitation, quality of life?

38 Is speech therapy or linguistics effective in improving/maintaining speech and communication skills and behaviour in people with dementia and in maintaining swallowing and chewing reflex for longer in people with dementia?

39 Can speech and language therapy assessment be effective in contributing valuable information for diagnosis of dementia?

Design

40 What are the most effective design features for producing dementia-friendly environments at both the housing and neighbourhood levels, that best support and enable people with dementia and carers to maintain quality of life, manage symptoms, minimise behavioural problems, slow progression of the illness and allow people to stay in their own homes for longer?
Including:
- for different cultural and ethnic groups
- design/adaptation of housing, signage, scenery, space, light

Diagnosis – early diagnosis

41 What is the impact of early diagnosis (and early/subsequent treatment/planning and support) on:
- health-related outcomes for people with dementia and their carers
- wider outcomes in society for people with dementia and carers/family
- health and social care services?

42 How can GPs/primary care provide a more effective service for diagnosis/early diagnosis of dementia, including faster referral to specialists when appropriate, including for all sub-types of dementia?

43 Would clear guidelines for GPs about diagnosis of dementia improve rate and accuracy of diagnosis/early diagnosis?

44 How could an effective self-diagnosis test (or a test that could be used by family or carers at home) for dementia be developed and what would be its effects?

45 Are there very early signs or precursors of dementia that could be used to indicate the onset of dementia?
Including:
- biological, physical, behavioural, neurological and cognitive precursors
- those that are able to differentiate dementia from other diseases.

46 How can people be educated to spot the signs of dementia earlier so that they go for assessment, diagnosis and treatment?

Diagnosis – improve diagnosis

47 What diagnostic tests/methods/strategies are clinically effective (and cost-effective) to improve diagnosis/early diagnosis of dementia?
Including:
- in different settings
- consideration of scans, biomarkers, blood tests, cognitive tests, family history, new techniques
- consideration of care/medical pathways
- different sub-types of dementia
- for different cultural and ethnic groups.

48 What is the best way to communicate a diagnosis of dementia, including who is the best person to communicate the diagnosis and where should it be delivered? How can relatives/carers best be involved in the diagnosis taking confidentiality into account?

49 Can changes in behaviour be used to aid diagnosis of dementia (perhaps using a list of known behaviour stages)?

50 How can the difference between normal age-related memory problems and dementia be distinguished?

Diagnosis – early diagnosis (continued)

51 Is diagnostic assessment of dementia more accurate when the observations of carers/partners/family are incorporated into the diagnostic procedures? Can diagnostic tests be developed that incorporate the observations of carers/partner/family?

52 How can best practice in dementia diagnosis, treatment and care and consideration of international practice be standardised across the UK?

53 Can blood tests to measure homocysteine levels contribute useful information for diagnosis of dementia?

54 How does dementia present in people with autism/Asperger's syndrome and what are the appropriate diagnostic criteria in these people?

55 How effective are memory clinics for the diagnosis and assessment of dementia, including differential diagnosis of different types of dementia and for providing support to people with dementia and carers?

Diagnosis – other

56 How accurate, reliable, valid and cost-effective are the assessment and diagnostic tools for dementia that are currently available?
Including:
- compared to each other
- compared to post-mortem data and cerebrospinal fluid (CSF) data
- scans and neuropsychological assessment.

57 What is the psychological impact of a diagnosis of dementia on the person, carers and relatives?

Emotional needs

58 How can the emotional needs of people with dementia best be assessed and what techniques can be used to meet these needs eg, improve self-esteem?

59 Does the cost of paying for care (including those at home/care homes) for those with sufficient assets impact on the emotional wellbeing/quality of life of people with dementia and their carers/families?

60 What is the level of awareness/understanding of people with dementia about their own life/surroundings/condition/emotions/thoughts (and of others) at all stages of the disease (even if they have lost language and struggle to communicate verbally)? How can this be measured?

Learning disabilities

61 What strategies are effective for the prevention, diagnosis, treatment and care of dementia in people with learning disabilities?
Including:
- consideration of pharmacological and non-pharmacological methods and service provision
- people with Down's syndrome.

Maintaining independence

62 What are the most effective and cost-effective components of care in people with dementia that keep the person with dementia as independent as they can be (while minimising stress to carers/families) at every stage of the disease and in all care settings eg, at home, in care homes, in the community?

63 Is it better for a carer to allow the person with dementia to manage their own day-to-day life as best as possible (even if they are struggling) or to 'take over'/do it for them in terms of progression of the disease/rate of deterioration?

64 Is assistive technology (eg devices to aid memory and aids for sight and hearing) for dementia effective for people with dementia in maintaining function/quality of life? How useful, acceptable and effective are assistive technology devices for carers, their neighbours, care staff and housing managers?

Managing behaviour

65 Is it better for carers to go along with the misconceptions of a person with dementia (eg believing someone is still alive when they are dead or when they are lying in bed believing that they are drowning in the bath) or to explain the reality in terms of reducing anxiety, agitation, improving quality of life, and other outcomes?

66 Is 'reality orientation' (as a specific therapy) effective for the management of behaviour 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 behaviour, quality of life during the day, and time to move to a care home?

69 What are effective ways to care for people with dementia who are in denial about their condition (care, medical and legal routes)?

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 behavioural management?

Managing behaviour (continued)

71   What are the most effective methods to manage sleep disorders and sleep patterns in people with dementia?

72   What are the most effective ways to manage 'wandering' or walking in people with dementia?

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?

74   How effective is a regular routine and consistent environment for managing symptoms/behaviour/outcomes for people with dementia compared to a less stable and consistent environment (for example, should the person with dementia be stimulated by changes, eg holidays and changes of scenery)?

Management of physical conditions

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?

76   What are the best ways to manage incontinence in people with dementia?

MCI (mild cognitive impairment)

77   What are the characteristics of MCI and early dementia and how can they be distinguished?

78   How can you predict whether a person with MCI will develop dementia or not?

Medication – effectiveness of current treatments

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?

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 behaviour)
- 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?

Medication – effectiveness of current treatments (continued)

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 optimised by linking to individual profiles?

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?

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?

Medication (general)

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?

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?

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?

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?

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

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

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

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

Medication (general) (continued)

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

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

Mental health/psychological therapies

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 those with dementia including slowing cognitive decline and progression of the disease?

96   Can traumatic emotional events be a trigger for dementia (eg bereavement, grief, divorce)?

97   Are counselling 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?

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

Monitoring

99   What methods are effective to assess and monitor people with dementia and their carers and the effect of treatment?
Including:
- the frequency of monitoring and length of assessments (shorter versus longer)
- which health and social care professionals are best placed to conduct monitoring
- the impact of monitoring on carers
- the effectiveness of home visits (for people with dementia and carers).

Prevention – lifestyle

100   Can the onset of dementia be prevented or delayed by dietary or nutritional factors?
Including:
- types of diet (eg Mediterranean, low fat), dietary patterns, components of diet eg macronutrients, caffeine, types of food eg fruit and vegetables, vitamins, minerals or nutritional/food supplements and drinks
- for different sub-types of dementia eg Alzheimer's, vascular, Lewy body
- in people with a family history/genetic risk factors for dementia
- the effectiveness of diet/nutrition started in older age compared to earlier in the life course.

Prevention – lifestyle (continued)

101 Is exercise/physical activity effective (and cost-effective) for preventing or delaying the onset of dementia?
Including:
- for different sub-types of dementia eg Alzheimer's, vascular, Lewy body
- the type (eg walking, dancing, outdoor activities) of and amount of physical activity that is effective
- the effectiveness of activity started in older age compared to earlier in the life course
- in people with a family history of dementia or genetic risk factors.

102 Are 'brain games' and other cognitive stimulation or learning processes effective at preventing or delaying the onset of dementia?
Including:
- for different sub-types of dementia eg Alzheimer's, vascular, Lewy body
- the types of cognitive stimulation processes that are effective
- people with family history/genetic risk factors for dementia
- the conversion of mild cognitive impairment (MCI) to dementia.

103 Is social interaction effective at preventing or delaying the onset of dementia?
Including the type of factors in the social environment that are most effective.

104 Can the onset of dementia be prevented or delayed by level of alcohol consumption?
What is the effect of alcohol consumption in older age compared to earlier in the life course?

105 Is there a link between amount of sleep/sleep patterns (including night shifts) and risk of dementia?

106 Can the onset of all types of dementia be prevented or delayed by controlling or minimising stress?
Including in people with a family history/genetic risk factors for dementia.

107 Do interventions to stop/prevent smoking help to prevent/delay onset/progression of dementia?

108 Are breathing exercises to increase oxygen flow around the body/brain effective to prevent/delay onset/manage dementia? At what age, if any, do these need to start to be effective?

Prevention – health risk factors

109 Do strategies to control vascular risk factors (eg high blood pressure and cholesterol) prevent/delay the onset of dementia?
Including:
- for different sub-types of dementia eg vascular, Alzheimer's, Lewy body
- in people with a family history/genetic risk factors for dementia
- in people with hypertension in middle age.

110 Do prevention strategies for diabetes prevent/delay onset of dementia?
Including for different sub-types of dementia eg vascular, Alzheimer's, Lewy body.

111 Are strategies to control weight (obesity, underweight and overweight) effective to prevent/delay onset of dementia?

Prevention – health risk factors (continued)

112 Are there any links between visual impairment/hearing impairment/dual sensory impairment and dementia?

113 What is the impact of heart disease and heart problems and their treatment (pacemaker and heart bypass surgery) on subsequent risk of dementia?

114 Is there a link between infections and risk of dementia?

115 Is there a link between migraine and the risk of dementia?

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?

Prevention – other risk factors

117 Could modification of environmental factors prevent/delay the onset of dementia? Including:
- electromagnetic fields, chemicals, pollution/vehicle fumes, lead, mobile phones, mobile phone masts, radiation and water sources
- in those with family history/genetic risk factors for dementia
- different sub-types of dementia
- at what stage in life do environmental factors have an effect.

118 Is there a link between where people live geographically and dementia?

119 Is there a link between exposure to aluminium (from any sources including medications, water, cooking utensils) and dementia?

120 Is there a link between autism/Asperger's syndrome and dementia?

121 Is there a link between socioeconomic status and dementia?

122 Are people from black and other ethnic minority groups at greater risk of dementia (including all types of dementia)?

123 Is there any link between an academic/intellectual personality or level of education and dementia in later life?

124 Do any particular personality traits appear to be common in people who eventually develop dementia?

Predictive tests

125 What tests can be used to predict whether a person will develop dementia in later life (including blood tests, cognitive tests, biomarkers, brain scans, genetic tests, new techniques) for all sub-types of dementia?

126 What tests/methods/strategies are effective to predict the rate of progression of dementia (eg rapid or slow progression) and response to therapy?

Screening

127 Is screening for dementia clinically effective (and cost-effective) for improving outcomes for dementia? At what age would it be most effective to start?
Including in people with a family history/genetic risk factors for dementia.

128 What tests are clinically effective (and cost-effective) for screening for dementia (including all sub-types) and improving outcomes for dementia? At what age would it be most effective to start?
Including in people with family history/genetic risk factors for dementia.

Treatment and care therapies

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.

130 What are the most effective ways to encourage people with dementia to eat/drink/maintain nutritional intake in all settings (including the role of professional and family carers) and what effect, if any, does this have on weight, physical functioning, behaviour and progression of the disease?

131 What is the impact of improved hydration (drinking of fluids) on dementia at all stages of the disease?

132 Is physical activity (including outdoor exercise) effective in the treatment and care of dementia, including effect on behavioural, physical, psychological symptoms, quality of life, progression of the disease?

133 Are 'brain games' and other cognitive stimulation or learning processes effective for the management of dementia (eg slowing cognitive decline and the progression of the disease, managing behaviour, anxiety and agitation, maintaining quality of life)?
Including:
- the types of cognitive stimulation that are effective
- which are effective in different settings eg at home or in care homes
- effectiveness compared to general activity/social groups
- the most effective mode of delivery eg one to one/groups/individually tailored.

Treatment and care therapies (continued)

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)?

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

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

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

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

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

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?

141 Is (amyloid) vaccination therapy effective for the treatment of dementia?

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.

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?

Young/early onset dementia

144 What are the risk factors for early onset dementia? Including any links with other illnesses eg autoimmune, neurological.

145 Is it better for young/early onset people with dementia to be cared for with other young/early onset people instead of in care homes/units with older people in terms of quality of life and outcomes?

146 What are the most effective methods (pharmacological and non-pharmacological) for treating and caring for young/early onset people with dementia in all settings?

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Age Related Diseases and Health Trust

Anchor

Association for Dementia Studies, University of Worcester

Bradford Dementia Group, University of Bradford

British Geriatrics Society

British Psychological Society

College of Mental Health Pharmacy

College of Social Work

Dementia Adventure

Dementia and Sight Loss Interest group

Dementia Pathfinder Community Interest Company

Dementia UK East Anglia PSIGE group
(Division of Clinical Psychology Faculty for Older People Psychology)

English Community Care Association (ECCA)

Foundations

Four Seasons Health Care

Frontotemporal Dementia Support Group

Greater Manchester West Mental Health Foundation Trust

HC-One care homes

Innovation Hub

Innovations in Dementia

Institute for Ageing and Health, Newcastle University

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Lewy Body Society

London Dementia in Intellectual Disabilities Special Interest Group

MHA

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NIHR Dementia & Neurodegenerative Diseases Research Network (DeNDRoN)

North East London Community Palliative Care Services

Parkinson's UK

Pick's Disease Support Group

Posterngate GP Surgery

Queen's University

Royal College of General Practitioners

Royal College of Nursing

Royal College of Occupational Therapists

Royal College of Psychiatrists

Scottish Clinical Dementia Research Network

Sheffield City Council

Sheffield Health and Social Care Foundation Trust

South Tyneside NHS Foundation Trust

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St Cheshire's Hospice

Surrey & Sussex Dementia Care

Surrey and Borders Partnership NHS Foundation Trust

Surrey and Borders Partnership NHS Foundation Trust

Taunton & Somerset NHS Foundation Trust

Tees, Esk and Wear Valleys NHS Foundation Trust

The Cochrane Collaboration

Thomas Pocklington Trust

WRVS

Young Dementia UK

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes).

The James Lind Alliance — Priority Setting Partnerships