What are some of the future priorities for dementia research?
Overview of the process

How did the project start?

What did we do - methods

Prioritisation

Next steps
History of initiative

- Public health representation on Research Advisory Committee
- Creation of Public Health Advisory Committee (multidisciplinary academic membership)
- Work programmes: systematic reviewing on risk and screening
- Staff at Alz Soc with interest and enthusiasm, increasing engagement with Society as whole
- JLA contact, making case and persuasion of Chief Executive
- HTA application
- Alz Soc underwriting and working with existing structures
- Collaborative effort – results being presented here
- First quick description of the JLA for orientation
What is the James Lind Alliance?

- JLA facilitate Priority Setting Partnerships.

- Involve people in deciding what gets researched:-
  - patients/service users
  - carers and relatives
  - healthcare professionals

- To identify and prioritise for research the *uncertainties* which they agree are the most important.

  - To agree a top 10 list of uncertainties for dementia research
What is the James Lind Alliance?

• Part of the Department of Health/NHS

• National Institute for Health research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC).

• [http://www.lindalliance.org](http://www.lindalliance.org)

• [www.twitter.com/LindAlliance](http://www.twitter.com/LindAlliance)
Who was James Lind?

• Scottish naval surgeon, about 250 years ago

• Early pioneer of clinical trials

• Conflicting ideas and unanswered questions about how to treat scurvy.

• Addressed the uncertainty by treating his patients within a clinical trial comparing six of the proposed remedies.

• His trial showed that oranges and lemons were dramatically better than the other supposed treatments.
• Who normally decides what gets researched?
  • Researchers
  • Pharmaceutical industry

The priorities of people with conditions and the people who treat and care for them can be very different.
The JLA priority setting process

- Set up steering group (protocol)
- Invite partners
- Identify uncertainties
- Format research questions
- Prioritise uncertainties
  - Interim prioritisation
  - Final prioritisation
The JLA priority setting process

• Promote priorities to researchers and funders
Dementia PSP steering group

- Katherine Cowan (chair) – JLA
- Denise Wilson (Dendron)
- Tony Bayer (Cardiff University)
- Nicola Hart, Claire King (Alzheimer’s Soc)
- Mark Fenton (UK DUETS)
- Claire Lawton (Cambridge and Peterborough NHS Foundation Trust)
- Graham Stokes (BUPA)
- Jill Manthorpe (Kings College London)
- Angelique Mavrodaris (University of Warwick)
- Carol Brayne, Louise Lafortune (University of Cambridge)
Dementia PSP objectives and scope

• To work with people with dementia, their carers/former carers, health and social care practitioners and members of the community from a broad population perspective

• To identify uncertainties around the prevention, diagnosis, treatment and care of dementia.

• Prioritise a top 10 list of uncertainties for dementia research.
UK Database of Uncertainties about the Effects of Treatments (UK DUETs)

- [http://www.library.nhs.uk/duets/](http://www.library.nhs.uk/duets/)

- Identified uncertainties from Dementia PSP to be entered into UK DUETS
Partner organisations

• Numerous stakeholders
• Representing patients/carers/clinicians/health and social care professionals/charities
• Initial awareness meeting (April 2012)
• Involved in dissemination of survey, prioritisation process.
Overview of the process

How did the project start?

What did we do - methods

Prioritisation

Next steps
How did we identify uncertainties

1. Survey – widely disseminated

2. Existing research recommendations
Dissemination of survey

• Alz Soc website – online or downloadable in paper format
• Stakeholder/partner groups
• Steering group contacts
• Under represented groups targeted
• (GP’s, old age geriatricians and psychiatrists, people with dementia, people with no direct experience of dementia and ethnic minority groups)
Identifying uncertainties – survey

Dementia Priority Setting Partnership

Do you have any questions about dementia that you have been unable to find answers for?

This partnership aims to work with people with dementia, their carers and former carers, health and social care professionals and the wider community to identify and prioritise the most important research questions for dementia. With the current ageing population, this will ensure that future research will address what is important to the whole community, not just researchers.

If you are interested in dementia, we would like to invite you to take part in this short survey and submit any questions about the prevention, treatment, diagnosis and care of dementia that you have been unable to find answers for.

By participating in this survey you are agreeing to allow us to publish the questions you identify in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs – www.library.nhs.uk/duets). Your name or organisations will not be published.

What do we mean by “unanswered questions”? We are looking for questions about the prevention, diagnosis, treatment and care of dementia that are currently unanswered by research evidence.

Here are some examples of unanswered questions for other health conditions:

- Is there a vaccine that can prevent prostate cancer?
- What is the optimal process for GP education and training for improved diagnosis and management of balance disorders?
- Which treatment is more effective for vitiligo: calcineurin inhibitors or steroid creams/ointments?
- How can stroke survivors and families be helped to cope with speech problems?
- What are the unintended consequences of screening for autism in very young children?
Identifying uncertainties – survey

What unanswered questions do you have about the prevention, diagnosis, treatment, and care of dementia? Please fill in any that you have in the correct box. (You can submit as many or as few as you like).

What question(s) about the prevention of dementia would you like to see answered by research?

What question(s) about the diagnosis of dementia would you like to see answered by research?

What question(s) about the treatment of dementia would you like to see answered by research?

What question(s) about dementia care would you like to see answered by research?
Identifying uncertainties – survey

Some questions about you

It would be very helpful for our research to know a little information about you so we can understand who has responded to our survey. We would be grateful if you could answer the following questions.

1. Which of these categories best describes you? (tick all that apply)
   - I am a person with dementia
   - I am a partner/relative/carer/former carer of someone with dementia
   - I am a healthcare professional working in the field of dementia
   - I have no direct experience of dementia, but I am interested in it as an issue
   - Other – please specify ___________

If you are a healthcare professional please go straight to question 7.
If you are a carer please answer the following questions on behalf of the person that you care(d) for.

2. What is your (or the person you care(d) for) gender?
   - Male
   - Female
   - Prefer not to say

3. What is your (or the person you care(d) for) age?
   - Under 40
   - 40-49
   - 50-59
   - 60-69
   - 70-79
   - 80-89
   - 90+
   - Prefer not to say

4. What is your (or the person you care(d) for) ethnicity?
   - White
   - Black
   - Asian
   - Mixed race
   - Chinese
   - Other ethnic group
   - Prefer not to say
Identifying the questions

• The survey was open from 1 April – 29 June 2012.

• “What questions about the prevention, diagnosis, treatment and care of dementia would you like to see answered through research?”

• 1,563 completed surveys

= 4,116 questions
### Survey respondents

<table>
<thead>
<tr>
<th>Respondents</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td></td>
</tr>
<tr>
<td>People with dementia</td>
<td>4.1</td>
</tr>
<tr>
<td>Carer/family/relative</td>
<td>76.0</td>
</tr>
<tr>
<td>Health care professional (+retired)</td>
<td>14.4</td>
</tr>
<tr>
<td>No direct experience</td>
<td>1.4</td>
</tr>
<tr>
<td>Other</td>
<td>2.9</td>
</tr>
<tr>
<td>Not answered</td>
<td>1.2</td>
</tr>
</tbody>
</table>
## Responses from healthcare professionals

<table>
<thead>
<tr>
<th>Profession</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
<td>7.2</td>
</tr>
<tr>
<td>Geriatrician</td>
<td>2.9</td>
</tr>
<tr>
<td>GP</td>
<td>2.4</td>
</tr>
<tr>
<td>Nurse</td>
<td>27.0</td>
</tr>
<tr>
<td>Old age psychiatrist</td>
<td>6.3</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>1.9</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>8.7</td>
</tr>
<tr>
<td>Social worker</td>
<td>3.4</td>
</tr>
<tr>
<td>Other</td>
<td>28.5</td>
</tr>
<tr>
<td>Not answered</td>
<td>11.7</td>
</tr>
</tbody>
</table>
Examples of questions (1)

• ‘Could there be a 'one stop' system for patients with dementia so that if they have to be admitted to hospital all their mental and physical treatment can be in one place? My mum was in a mental health hospital for depression/dementia but when she got a chest infection and later pneumonia she had to be transferred to another hospital for medical care.’
Examples of questions (2)

• ‘Is anyone looking in detail at occupation? Particularly those who have worked for years with electric cabling running by heads, chests, bodies. The Magnetic part of the field of the EMF will trigger molecular spin, Reactive Oxygen species (free radicals to you) and can cause microtubules to act as waveguides for specific frequencies.’
Collating the questions

- Removed questions that were out of scope.
- Categorised the questions.
- Reformatted questions where appropriate (PICO format).
- **Combined duplicate or similar questions.**
- Removed questions that can already be answered.
- Removed questions that were only submitted by 1 or 2 people.
<table>
<thead>
<tr>
<th>Question</th>
<th>Asked by:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive stimulation</strong></td>
<td>11 x HC profs</td>
</tr>
</tbody>
</table>
| 1 Are ‘brain games’ and other cognitive stimulation processes effective at delaying or slowing the onset of dementia?  
- Including for different sub-types of dementia  
(crossword puzzles, Scrabble, Sudoku, jigsaws, reading, studying new subjects, other puzzles, memory games, learning a language, hobbies, using left hand instead of right (and v/v), playing musical instrument, brain training games)  
(Vascular dementia, Lewy body dementia, Alzheimer’s disease) | 51 x part/rel/carer  
2 x pwd  
2 x other  
2 x no direct exp |
Collating the questions

- Removed questions that were out of scope.
- Categorised the questions.
- Reformatted questions where appropriate (PICO format).
- Combined duplicate or similar questions.
- **Removed questions that can already be answered.**
- Removed questions that were only submitted by 1 or 2 people.

= 146 questions
Checking that questions are uncertainties

• The JLA definition of an uncertainty is that:
  – no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty about the effects of treatment exists
  – up-to-date systematic reviews of research evidence show that uncertainty exists

• Comprehensive literature searches carried out to identify relevant systematic reviews

• All questions checked against systematic review evidence.
Collating the questions

- Removed questions that were out of scope.
- Categorised the questions.
- Reformatted questions where appropriate (PICO format).
- Combined duplicate or similar questions.
- Removed questions that can already be answered.
- Removed questions that were only submitted by 1 or 2 people.

= 146 questions
Identifying uncertainties (2)

• Research recommendations from existing systematic reviews of research evidence on dementia.
Overview of question management

Collection of questions (Survey, research recommendations)

Data cleaning, combining and formatting of research questions

Check against existing systematic reviews

True uncertainties

Prioritisation

Out of scope

‘Answerable questions’

UK DUETS

Feedback to Alzheimer’s Society
Overview of the process

How did the project start?

What did we do - methods

Prioritisation

Next steps
Prioritising the questions

Interim prioritisation

• 36 organisations participated who represent the views of people with dementia and their carers or health and social care practitioners.

• From the list of 146 questions, each organisation was asked to rank their top 10.

= 25 questions
Prioritising the questions

Final Prioritisation

Workshop – Wednesday 12 June 2013
To prioritise the top 10 questions out of a list of 25.

Who took part?

• Clinicians and care practitioners eg Old age psychiatrist, clinical psychologist, geriatrician, GP, nurse, social worker, occupational therapist.
• People with dementia and their carers.
The workshop

• An opportunity for different parties to:
  - express their views
  - hear different perspectives
  - think more widely about treating or helping people with dementia beyond their own experiences

• Rigorous format
• Encourage open debate
• Reaching a group decision is challenging

= 10 questions
How did we do it?

Part 1

Dementia Priority Setting Partnership - Pre Workshop Exercise

INDIVIDUAL RANKING OF UNCERTAINTIES FOR THE DEMENTIA WORKSHOP ON 12 JUNE 2013

Please spend some time before the workshop reviewing these uncertainties about the prevention, diagnosis, treatment and care of dementia. Rank them from 1-25, 1 being the most important in your opinion and 25 being the least important, for research to address. Make a note of any comments in the far right hand column. Please bring this with you to the workshop.

<table>
<thead>
<tr>
<th>ID</th>
<th>Uncertainty</th>
<th>Year ranking (1-25)</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Are non-pharmacological (non-drug) or alternative therapies effective and cost-effective for the treatment and management of dementia?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>Can the onset of dementia be prevented or delayed by dietary or nutritional factors?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>Do improved conditions (e.g. salaries, career structure and training) for care staff improve quality of care?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>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 hospitals?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>How can GPs/primary care provide a more effective service for diagnosis/early diagnosis of dementia, including faster referral to specialists when appropriate?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
How did we do it?

Part 2 & 3
How did we do it?

Part 4

alzheimers.org.uk
The top 10 priorities

Dementia Priority Setting Partnership

Alzheimer's Society, through the James Lind Alliance, has brought together the voice of people with dementia and their carers with health and social care practitioners to identify some of the priorities for future dementia research.

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?
4. What non-pharmacological and/or pharmacological (drug) interventions are most effective for managing challenging behaviour in people with dementia?
5. What is the best way to care for people with dementia in a hospital setting when they have acute health care needs?
6. What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake?
7. What are the most effective ways of supporting carers of people with dementia living at home?
8. What is the best way to care for people with advanced dementia (with or without other illnesses) at the end of life?
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?
10. What are the most effective design features for producing dementia-friendly environments at both the housing and neighbourhood levels?

alzheimers.org.uk/dementiapsp
‘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.’

‘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.’

Participants from the workshop
Overview of the process

How did the project start?

What did we do - methods

Final prioritisation

Next steps
Influence of previous partnerships?

• Urinary Incontinence
  • Six of the top 10 priorities have received funding.
  • A number of systematic reviews have been initiated or are being updated.
  • Several questions are under consideration by the NIHR for research commissioning calls.
  • The top 10 has been recognised by two international academic groups that have an interest in incontinence research.
Influence of the dementia partnership?

- Promote investment in dementia research
- Increase investment in care research
- Ensure research addresses questions that are important to those affected
- Promote collaborative working
For more information visit www.alzheimers.org.uk/dementiapsp or contact research@alzheimers.org.uk

Thank you!