The Ministerial Advisory Group on Dementia Research: Headline Report

Circulation List

Description
The Report identifies the main challenges facing dementia research and sets out a range of actions designed to address them, summarised in the Route Map for Dementia Research (Annex A). The actions will be taken forward by a wide range of different organisations with clear time lines for delivery.

Cross Ref

Superseded Docs

Action Required
Adoption by DH, NIHR and other relevant research organisations and charities

Timing

Contact Details
Carol Lupton
Policy Research Programme
Area 132, Richmond House
79 Whitehall
London
SW1A 2NS
www.dh.gov.uk/en/Publicationsandstatistics/Publications/

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FOREWORD

In 2009 I wrote the foreword to Dementia 2010, a study by the Alzheimer’s Research Trust on the prevalence and cost of dementia. This presented a stark finding: Dementia costs UK plc £23 billion a year. And this is just the economic cost; the real social cost, for the 820,000 people living with the condition and the many others whose lives it touches, is incalculable.

Dementia continues to pose many challenges - to scientists, policy-makers, and above all to those living with the condition and their carers. Left unaddressed, these costs will continue to grow. Leading scientists are already warning that the NHS will struggle to cope if the prevalence of dementia continues to rise as predicted.

For this reason, the Coalition Government has picked up the last Government’s dementia strategy and is driving it forward strongly. However, while this offers the prospect of a better model of care, we also must focus on the inexorable rise in the demand for treatment and care.

Human ingenuity and scientific discovery are at the heart of this: we need to understand more about the causes of this terrible condition, about possible cures and about ways to provide the best possible care. This requires investment in high quality research.

Dementia costs the UK twice as much as cancer, three times as much as heart disease and four times as much as stroke - yet dementia research funding has not gone as far as these. This is why the Coalition Government is committed to taking the necessary steps to prioritise dementia research.

The Ministerial Advisory Group on Dementia Research was set up to find ways to increase the volume and impact of high quality research. The Group has now completed its work and has proposed a very comprehensive set of actions to take dementia research forward. These are set out in this Headline Report and summarised visually in the ‘Route Map for Dementia Research’.

Many of the actions in the Route Map are already underway - led by a wide range of partners. These include significant new funding opportunities and a national Dementia Research Portal to inform the research community about new developments. Work is also being undertaken to improve collaboration between researchers and support their work, as well as to strengthen the translation of research to care and treatment, linking with the implementation of the National Dementia Strategy.

I am delighted at these developments and grateful to all who have contributed to the Advisory Group’s work. As this report demonstrates, there is a clear sense of direction and collective purpose. I am confident that together we will achieve a significant step forward for UK dementia research and for those living with this devastating condition.

Paul Burstow MP
Minister of State for Care Services
Chair, Ministerial Advisory Group on Dementia Research
BACKGROUND

The Ministerial Advisory Group on Dementia Research (MAGDR) was established in February 2010 to consider ways to increase the volume and impact of high quality dementia research. It aimed to build on the momentum begun at the earlier Ministerial Summit on Dementia Research in 2009. The Group comprised scientists, representatives of funding bodies, charities and industry, as well as people with experience of living with dementia. From the outset, MAGDR was positioned as a means to bring key interests together to develop shared solutions to common challenges.

Between the main meetings of MAGDR, subgroups progressed work in five key areas:
- agenda prioritisation;
- funding opportunities;
- public engagement;
- improved translation;
- better ways of working.

The subgroups were tasked to propose specific actions, with clear goals and timelines, for both the short and longer-term. Members recruited additional expertise, as required, and drew on key documents such as the 2008 MRC Strategic Review of Neurodegeneration\(^1\), the 2009 National Dementia Strategy\(^2\), and the report of the 2009 Ministerial Summit on Dementia Research\(^3\).

Initial subgroup proposals were discussed at the second meeting of MAGDR in September 2010 where further work was identified, including on cross-cutting issues. Each subgroup met on at least one further occasion and many conducted scoping exercises and/or undertook further consultation. The Dementia Research Workshop, organised by the National Institute for Health Research (NIHR) in January 2011, attended by the Minister for Care Services, offered the opportunity for subgroup chairs to consult the dementia research community more widely as well as for researchers to hear about a new NIHR funding initiative.

The final reports of the individual subgroups were presented to the last meeting of the MAGDR in March 2011. The proposals and actions agreed have been brought together into a visual ‘Route Map for Dementia Research’, with clear timelines for delivery. This is attached at Annex A. The following summary describes the main issues and the actions that underpin the Route Map.

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ISSUES AND ACTIONS

1. Strengthen Collaboration and Coordination

Issues Identified

Care and treatment pathways in dementia are complex - spanning acute, primary, community health and social care sectors - and provided by a range of statutory and/or non-statutory bodies. The key role of the commercial sector is a particular feature, including providers of care, equipment and devices as well as pharmaceuticals. Better collaboration between the public and commercial research sectors, with greater mutual transparency, therefore seems vital. The current global repositioning of ‘biopharma’ to externalise its research activity, provides significant opportunities in this respect. Opportunities to develop pre-competitive consortia on animal models, biomarkers and disease mechanisms, and to increase public access to data from completed industry studies should actively be sought. Attention also needs to be given to improved consistency of support for research in residential care homes and in non-NHS settings more generally.

Dementia research is also characterised by considerable methodological and disciplinary diversity. Effectively addressing the main research questions will need to draw on a wide range of scientific areas. Collaboration, between disciplines and specialities, will be key to collective progress. This will be assisted by work towards the development of standard - or compatible - systems, methods and platforms and, where relevant, pooled data and expertise. Further easing of any regulatory bureaucracy disproportionately affecting particular areas of dementia research, such as animal/ tissue work and multi-centre research, will be helpful.

Actions Agreed

The NIHR’s Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) will lead improvement work on the quality and consistency of support provided to research in the field, via projects on ‘Integrating Networks and Embedding Research in Clinical Practice’ (INTERACT) and ‘Enabling Research in Care Homes’ (ENRICH). ENRICH will aim to facilitate research in the care home sector, for example by developing networks, clarifying funding and encouraging greater harmonisation of record keeping. An early output will be guidelines for researchers in the sector. More generally, the issue of regulation is being addressed by actions related to research regulation and governance in the ‘Plan for Growth’ and the NIHR will continue to explore ways to streamline bureaucracy further at a generic level.

The Medical Research Council (MRC) is leading work on public/private collaboration with the Association of the British Pharmaceutical Industry (ABPI), including on data/information-sharing and on the possibility of identifying common targets for drugs/devices. An initial joint report has already been produced and will be followed by a UK ‘asset-map’ detailing current expertise and bio & data resources across the two sectors. The ‘asset map’ will identify areas of opportunity for public/private partnerships, with a view to establishing and funding pre-competitive consortia in selected areas. The MRC is also leading work with EU partners on international collaboration under the EU Joint Programming on Neurodegeneration (JPND)

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4 http://cdn.hm-treasury.gov.uk/2011budget_growth
initiative. On behalf of the JPND, this will produce a European strategic agenda by the end of 2011 that will inform EU-wide research priorities and collaboration between national bodies.

2 Embed Research in Treatment and Care

Issues Identified

Collective work is needed to engender a more thoroughgoing culture of research in the field, with the ultimate aim of embedding the ‘delivery’ of research across the full care pathway and in all service sectors. Centrally, this will require more routine and systematic recruitment of patients and carers/controls to research at the earliest possible stage, including prospective recruitment for brain donation. More effective coordination of current brain tissue donations and the promotion of tissue availability will be central. The National Dementia Strategy (NDS) provides new opportunities to embed ‘research delivery’ mechanisms in defined care pathways and to increase research activity by core care/clinical staff. System incentives, with explicit links to outcomes, will help to strengthen the alignment of research and care pathways, especially in primary and social care.

Joint efforts must also continue on the more effective translation of research-based evidence across all stages of the care cycle, including end of life. Smarter and swifter dissemination of research-based findings is essential, differentiated by professional/sector audience. Effective translation needs to be supported by better education and training, particularly of non-specialist staff, with general practitioners and other community based care professionals as an early focus.

Actions Agreed

The MRC will lead work with the charities on the co-ordination of existing UK brain banking facilities and provide new funding for its own brain banks. The NIHR’s DeNDRoN will lead on the development of local lists of patients/carers willing to be approached to take part in research. This will be undertaken by the ‘Recruitment and Feasibility Tools’ (RAFT) project, in collaboration with local services. Early outputs will be an evidence-based business case for these ‘consent lists’ and proposals to support their federation. The MRC, supported by RAFT, will establish links between the consent lists and the UK brain bank network, to encourage brain donation for research. Under project INTERACT, the Department of Health (DH) and NIHR’s DeNDRoN will establish formal links between the DeNDRoN Coordinating Centre and the National Dementia Strategy (NDS) Implementation Team. The ultimate aim is for patients and their carers to be more routinely offered the opportunity to participate in research by core clinical & care staff in all areas of England.

The DH will work with professional bodies such as the Royal Colleges to develop evidenced-based decision-support tools. The development of ‘bespoke’ strategies for different care sectors will begin with production of a dementia e-resource for general practitioners. The DH will also collaborate with social care bodies in a dementia skills group designed to raise the quality of practice in non-clinical settings, including at end of life, linked to a wider Workforce Advisory Group. The Alzheimer’s Society (AS) will work with the DH on the development of evidence-based training materials for care home staff.
3 Grow Capacity and Capability

Issues Identified
Dementia research is not unique in its need to attract the best scientists from a wide range of disciplines. But recent advances in understanding the condition have increased the tractability of the research questions involved and provide new opportunities for quality scientists from contiguous fields. These should be actively exploited. Existing capacity-building schemes should be assessed in relation to sector need, although there appears to be particular demand for neuropathologists, economic analysts and care services researchers. Nursing and allied professionals should be supported to increase research activity, ideally building on existing areas of critical mass. Research leadership needs to be strengthened across the field, with formal and informal links between existing research leaders being more actively encouraged.

Actions Agreed
The NIHR will contribute to building capacity by allocating a number of Academic Clinical Fellowships and Clinical Fellowships to trainee to doctors undertaking dementia-relevant clinical research training programmes. The allocation of these ‘dementia posts’ will be made in Summer 2011 and trainees recruited from November 2011 onwards. All funders will regularly review whether existing support for research training is sufficient to meet capacity needs in key underpinning disciplines such as welfare economics. The Alzheimer's Society will continue to lead a mentoring programme for care researchers new to dementia, supported by the DH, NIHR and NHS Education for Scotland.

4 Harness Existing Resources

Issues Identified
While there is no evidence that bids for dementia research funding are disadvantaged compared with other disease areas, ways should be sought to increase the success of the dementia research community in competitive funding contexts. Funders need more systematically to inform the full range of relevant scientific communities about forthcoming research opportunities and allow sufficient time for them to prepare high quality bids. There is need for greater clarity on funding criteria/conditions and it is important to ensure that these do not unfairly discriminate against particular scientific areas. Better co-ordination between funders on priorities for dementia research will enhance effective use of resources.

In turn, the research community needs actively to pursue funding opportunities in related areas like public health which are currently experiencing growth, and to increase take up of existing support services such as research design or writing groups. Greater exploitation of available data resources, including from existing longitudinal and cross-sectional studies, would also be beneficial, in particular to help identify risk and predictive factors.
**Actions Agreed**

The MRC has committed to a 10% increase in its funding for neurodegeneration research by March 2015 and will fund new collaborative research through its ‘Centres of Excellence in Neurodegeneration’ (COEN) initiative. The MRC will also fund new cross-border collaborative research, with EU partners, via the EU Joint Programming initiative (JPND). The NIHR has launched a themed call on dementia research across seven of its main funding Programmes, supported by a national Workshop and an extended application period. The NIHR will also fund up to four Biomedical Research Units in dementia, jointly up to a maximum of £20m over five years, subject to receipt of suitable bids. NIHR's DeNDRoN will work to extend the reach of support such as writing groups to all clinically relevant science areas. All partners will promote funding opportunities via a new Dementia Research Portal (to be led by Alzheimer's Research UK) and take account of the priorities identified via the MAGDR process in formulating funding agendas.

5 **Engage the Public**

**Issues Identified**

Finally, collective work is needed to extend public engagement in dementia research. This needs to increase public understanding of the value of research and the importance of brain/tissue donation in particular. There also needs to be more direct involvement of the public in research, both as research participants and more actively in the research process itself. There is already considerable experience of the very positive contribution that can be made by patients and/or carers, with appropriate support, in the planning and commissioning of research and in the effective translation of its messages.

To maximise reach, dementia research messaging could usefully link with wider public health promotion strategies on risk reduction/prevention. Collaboration in broader campaigns on healthy diet, obesity, cardiovascular risk etc could be developed under the banner of 'healthy body: healthy mind'. Messages should utilise new media/social networking and professional communications expertise and be carefully targeted at particular sub-populations/issues, such as longer-term behavioural change in young people. Campaigns will need, however, to guard against the adoption of a ‘deficit model’ of public understanding, which assumes that the provision of more information necessarily leads to the anticipated actions 6.

**Actions Agreed**

Carers of people living with dementia were actively involved in the work of the MAGDR and its subgroups, contributing to the development of the Route Map and Headline Report. The DH already benefits from active patient and service user/carer involvement in the research it commissions via its Policy Research Programme, and the Alzheimer’s Society is working with NIHR and INVOLVE7 to support Patient and Public Involvement (PPI) in the NIHR themed call on dementia research.

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7 INVOLVE is a national advisory group which supports greater public involvement in NHS, public health and social care research, funded by the National Institute for Health Research.
In addition, charities will lead work with partners to identify opportunities for the dissemination of evidenced-based messages on dementia, including a national campaign linking dementia to wider public health messages on related conditions such as circulatory disease and diabetes. The Economic and Social Research Council (ESRC) will support this process by signposting the evidence for behavioural change interventions. Charities will also consider specific partnership projects to maximise collective resources, and will work with NIHR DeNDRoN's project RAFT to broaden public engagement in the development of local ‘consent to research’ lists.
CONCLUSION

The Ministerial Group was established from the outset as a time-limited initiative. At its meeting in March 2011, it was agreed that its central task had been achieved and that the Group should be formally 'stood down'. However, it was also agreed that the implementation of the Route Map should be monitored closely, in order to ensure momentum and that, at a point 12 months after its publication, the Group will reassemble once more to assess collective progress against the agreed actions. This follow-up meeting will be held in July 2012 and will produce a published account of progress against the Route Map. Monitoring will remain in place, however, until the last actions are due to be completed at the end of 2012.

The main proposals made by the Ministerial Group are summarised, with clear timelines, in the attached 'Route Map for Dementia Research'. These represent a comprehensive set of actions to address the key issues identified by the dementia research community. They are not however a list of requirements for Government action. Rather they involve a wide range of bodies contributing a variety of resources and expertise, according to their respective means and particular areas of interest. As such, the experience of MAGDR has demonstrated the considerable value that can be added by joint action on shared areas of challenge. If the Route Map is to make a real difference to the health of dementia research, it will require all those involved to continue to work actively together on the implementation of its collectively agreed actions.
Ministerial Advisory Group: Route Map for Dementia Research

Agreed Action Area

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Strengthen Collaboration and Coordination

1. **improve consistency of support to field (led by NIHR-DeNDRoN)**
   - NIHR-DeNDRoN project INTERACT established
   - review NIHR-DeNDRoN support to field
   - improve consistency of delivery mechanisms across all Clinical Research Networks in English regions
   - common systems/methods/platforms developed
   - greater pooling of data & resources

2. **support research in non-NHS sector (facilitated by NIHR-DeNDRoN)**
   - NIHR-DeNDRoN project ENRICH established
   - clarify funding & support arrangements for non-NHS contexts
   - create & disseminate guidance for care home research
   - increase common data/record collection across non-NHS sector
   - network of research-enabled care homes established in England

3. **increase collaboration between public & private research sectors (led by MRC & ABPI)**
   - initial meeting held & report produced with proposals for improved collaboration
   - produce UK asset map of existing expertise and resources
   - disseminate existing data & info-sharing protocols
   - use asset map to identify opportunities for public/private partnerships, including establishment of pre-competitive consortia

**Abbreviations**

NIHR = National Institute for Health Research
DeNDRoN = Dementia and Neurodegenerative Diseases Network
ENRICH = Enabling Research in Care Homes
INTERACT = Integrating Networks and Embedding Research in Clinical Practice
ABPI = Association of the British Pharmaceutical Industry
MRC = Medical Research Council
Ministerial Advisory Group: Route Map for Dementia Research

Agreed Action Area

Review Period 1
Jan 2011 – June 2011

Review Period 2
July 2011 – Dec 2011

Review Period 3
Jan 2012 – June 2012

Review Period 4
July 2012 – Dec 2012

[green = delivered]

Grow Capacity and Capability

7. develop capacity
   - prioritise dementia in NHRR Biomedical Research Units call
   - up to four new NHRR Biomedical Research Units operational, depending on quality of bids

8. attract/support new researchers into field (all funders)
   - continue AS mentoring scheme for new dementia care researchers;
   - extend NHRR-DeNDRoN writing groups to all clinically relevant science areas
   - allocate NHRR Academic Clinical Fellowships/Clinical Lectureships for trainee doctors in dementia-relevant fields;
   - begin recruitment of trainees
   - promote opportunities to researchers in contiguous fields via new Dementia Research Portal

9. review and monitor capacity & capability needs (all funders)
   - assess existing capacity-building schemes;
   - review funding for underpinning disciplines
   - ARUK and AS to lead work on growing capacity in the area of ‘bench to bedside’

AS = Alzheimer’s Society  ARUK = Alzheimer’s Research UK
Ministerial Advisory Group: Route Map for Dementia Research

**Agreed Action Area**

**Review Period 1**
Jan 2011 – June 2011

**Review Period 2**
July 2011 – Dec 2011

**Review Period 3**
Jan 2012 – June 2012

**Review Period 4**
July 2012 – Dec 2012

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**Harness Existing Resources**

10. Increase access to existing resources (all funders)
   - Launch new NIHR Themed call in dementia; support call with national workshop

11. Promote existing opportunities & resources (ARUK lead)
   - Establish working group to develop new Dementia Research Portal
   - Dementia Research Portal established; longer lead-in times allowed for preparation of research bids
   - Existing/new opportunities for funding & support promoted via Portal

12. Agree/promote priority research areas (led by MRC with EU partners)
   - Launch call for proposals under EU 7th Programming on Neurodegeneration Initiative (JPND)
   - Produce EU strategic research agenda to inform priorities and collaboration; map existing resources and opportunities across EU under JPND
   - Disseminate priority topics/areas via Dementia Research Portal; fund UK contribution to new collaborative cross-border research through JPND

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COEN = Centres of Excellence in Neurodegeneration
Ministerial Advisory Group: Route Map for Dementia Research

Agreed Action Area

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[green = delivered]

Engage the Public

13. Promote dementia research to the public (led by Charities, with DH and Research Councils)
- Develop & disseminate messages on brain banking
- ESRC to support with evidence on behaviour change
- Work on lifestyle interventions/measures for care home populations
- Launch major publicity campaign, linking dementia with wider public health issues
- Pursue opportunities for partnerships with charities working outside dementia

14. Engage the public actively in dementia research (led by Charities)
- NIHR-INVOLVE to ensure active PPI in studies commissioned under NIHR Dementia Themed Call
- Work with NIHR-DeNDRoN to broaden PPI/carer engagement in the development of local patient list

15. Improve coordination of brain/tissue donation (led by MRC, with NIHR-DeNDRoN project RAFT)
- Improve coordination of existing UK brain bank facilities
- MRC to provide new funding to existing MRC brain bank
- Develop links between the UK Brain Bank network and local ‘consent to research lists’

PPI = Patient and Public Involvement
ESRC = Economic and Social Research Council
NIHR-INVOLVE = Supporting public involvement in NHS public health and social care research
MINISTERIAL ADVISORY GROUP ON DEMENTIA RESEARCH

Membership

Paul Burstow, MP (Chair)    Minister of State for Care Services
Adrian Alsop    Director of Research, Economic and Social Research Council
Professor Clive Ballard    Director of Research, Alzheimer's Society
Dr Peter Barnes    Medical Director, Janssen-Cilag Ltd
David Behan    Director General for Social Care, Local Government and Partnerships, DH and Chair of the National Dementia Strategy
Professor Alistair Burns    Professor of Old Age Psychiatry, University of Manchester and Department of Health National Clinical Director for Dementia
Dr David Cox    Deputy Director - Research Faculty Policy & Implementation, National Institute of Health Research
Professor Dame Sally C Davies    Director General, Research and Development, Department of Health
Steve Ford    Chief Executive, the Parkinson's Disease Society
Professor James Goodwin    Head of Research, Age UK
Baroness Sally Greengross    Vice Chair, All Parliamentary Group on Dementia and Older People
Professor Chris Kennard    Chair of the Neuroscience and Mental Health Board, Medical Research Council
Professor John Williams    Head of Clinical Activities, Wellcome Trust
Dr Declan Mulkeen    Director of Research and Training, Medical Research Council
Baroness Elaine Murphy    Secretary, All Party Parliamentary Group on Mental Health, House of Lords
Professor Martin Rosser    Director of the NIHR Dementia and Neurodegenerative Diseases Research Network (DeNDRoN)
Noreen Siba    Managing Director, International Longevity Centre UK
Rebecca Wood    Chief Executive, Alzheimer's Research UK and Chair of UKARF Working Group on Dementia Research
Barbara Woodward-Carlton    Lay member of NIHR DeNDRoN Clinical Studies Group (Dementia)

In attendance:

Dr Robin Buckle    Head of Neuroscience and Mental Health, Medical Research Council
Jerry Bird    Project Manager, Social Care; Local Government & Care Partnerships Directorate, Department of Health
Dr Carol Lupton    Senior Principal Research Officer, Policy Research Programme. Research and Development Directorate, Department of Health
Clare Croft-White    Scientific advisor to the Policy Research Programme (secretariat)
### MINISTERIAL ADVISORY GROUP ON DEMENTIA RESEARCH

**Sub-group participants**

#### Subgroup 1: Priority topic setting

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<tr>
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<tr>
<td>Prof Chris Kennard (Chair)</td>
<td>MRC Neuroscience and Mental Health Board &amp; University of Oxford</td>
</tr>
<tr>
<td>Dr Adrian Alsop</td>
<td>Economic and Social Research Council</td>
</tr>
<tr>
<td>Prof Clive Ballard</td>
<td>Alzheimer’s Society &amp; King’s College London</td>
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<tr>
<td>Dr Kieran Breen</td>
<td>Parkinson’s UK</td>
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<tr>
<td>Dr Rob Buckle</td>
<td>MRC</td>
</tr>
<tr>
<td>Prof Alistair Burns</td>
<td>DH Clinical Director for Dementia &amp; University of Manchester</td>
</tr>
<tr>
<td>Dr Shewly Choudhury</td>
<td>Wellcome Trust</td>
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<tr>
<td>Dr Peter Connelly</td>
<td>Chair of the Scottish Dementia Research Network</td>
</tr>
<tr>
<td>Prof Peter St George Hyslop</td>
<td>University of Cambridge</td>
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<tr>
<td>Prof James Goodwin</td>
<td>Age UK</td>
</tr>
<tr>
<td>Prof Cornelius Katona</td>
<td>NIHR DeNDRoN Dementias Clinical Studies Group</td>
</tr>
<tr>
<td>Prof Keith Lloyd</td>
<td>NISCHR, Welsh Assembly Government</td>
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<tr>
<td>Mrs Lynne Ramsey</td>
<td>Lay representative</td>
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<tr>
<td>Dr Simon Ridley</td>
<td>Alzheimer’s Research UK &amp; UKARF Dementia Working Group</td>
</tr>
<tr>
<td>Prof Gordon Wilcock</td>
<td>University of Oxford</td>
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<tr>
<td>Prof Julie Williams</td>
<td>Alzheimer’s Research UK</td>
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#### Subgroup 2: Engaging the Public

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<tr>
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<tr>
<td>Rebecca Wood (Joint Chair)</td>
<td>Alzheimer’s Research UK</td>
</tr>
<tr>
<td>Prof Clive Ballard (Joint Chair)</td>
<td>Alzheimer’s Society</td>
</tr>
<tr>
<td>Steve Ford</td>
<td>Parkinson’s UK</td>
</tr>
<tr>
<td>Prof James Goodwin</td>
<td>AGE UK</td>
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<tr>
<td>Joe Korner</td>
<td>The Stroke Association</td>
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<tr>
<td>Dr Craig Ritchie</td>
<td>Imperial College London</td>
</tr>
<tr>
<td>Prof John Starr</td>
<td>Scottish Dementia Clinical Research Network</td>
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#### Subgroup 3: Accessing existing funding and support

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<tr>
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<tr>
<td>Dr David Cox (Chair)</td>
<td>NIHR</td>
</tr>
<tr>
<td>Dr Kieran Breen</td>
<td>Parkinson’s UK</td>
</tr>
<tr>
<td>Dr Rob Buckle</td>
<td>MRC</td>
</tr>
<tr>
<td>Dr Shewly Choudhury</td>
<td>Wellcome Trust</td>
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<tr>
<td>Jim Jackson (deceased)</td>
<td>Alzheimer’s Scotland</td>
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<tr>
<td>Dr Hilary Lapsley</td>
<td>Scottish Government, Health Directorate</td>
</tr>
<tr>
<td>Prof Simon Lovestone</td>
<td>King’s College London</td>
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<tr>
<td>Beverly Luchmun</td>
<td>Welsh Office R&amp;D for Health &amp; Social Care</td>
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<tr>
<td>Prof John O’Brien</td>
<td>NIHR DeNDRoN</td>
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<tr>
<td>Prof Martin Rosser</td>
<td>NIHR DeNDRoN</td>
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<tr>
<td>Jo Swinhoe</td>
<td>Alzheimer’s Society</td>
</tr>
<tr>
<td>Dr John Wilkinson</td>
<td>Department of Health</td>
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<tr>
<td>Prof Julie Williams</td>
<td>Cardiff University Neuroscience Centre</td>
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<tr>
<td>Rebecca Wood</td>
<td>Alzheimer’s Research UK</td>
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Subgroup 4: Developing better ways of working

Prof Martin Rossor (Chair) NIHR DeNDRoN
Prof Clive Ballard Alzheimer’s Society
Dr Peter Barnes ITS, Johnson & Johnson
Dr Rob Buckle MRC
Prof Alistair Burns Department of Health
Dr Shewly Choudhury Wellcome Trust
Prof Steve Iliffe NIHR DeNDRoN
Piers Kotting NIHR DeNDRoN (Secretariat)
Prof Ian McKeith NIHR DeNDRoN
Dr Catherine Moody MRC
Dr Declan Mulkeen MRC
Barbara Pointon Alzheimer’s Society Ambassador
Prof John Williams Wellcome Trust
Rebecca Wood Alzheimer’s Research UK

Subgroup 5: Translating research into practice

Prof Alistair Burns (chair) Department of Health
Prof Clive Ballard Alzheimer’s Society
Charlotte Duggan Department of Health
Prof James Goodwin AGE UK
Martin Green ECCA
Joe Korner The Stroke Association
Prof Louise Robinson University of Newcastle
Noreen Siba International Longevity Centre UK
Prof George Tadros Queen Elizabeth Psychiatric Hospital, Birmingham
Rebecca Wood Alzheimer’s Research UK
Barbara Woodward-Carlton NIHR DeNDRoN Clinical Studies Group (Dementia)