



**THE MINISTERIAL ADVISORY GROUP
ON DEMENTIA RESEARCH**

Headline Report

The Ministerial Advisory Group on Dementia Research: Headline Report

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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.

¹ '*Strategic Review of Neurodegeneration: Report of the Strategic Review Group*', Medical Research Council February 2008: <http://www.mrc.ac.uk/Ourresearch/Boardpanelsgroups/NMHB/Programme/Neurodegeneration/index.htm>

² '*Living well with dementia – a National Dementia Strategy*', Department of Health, February 2009: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

³ '*Report from the Ministerial Summit on Dementia Research*', International Longevity Centre UK, November 2009: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/@sta/@perf/documents/digitalasset/dh_108581.pdf

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'*⁴ 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 produced⁵ 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)

⁴ http://cdn.hm-treasury.gov.uk/2011budget_growth

⁵ MRC/ABPI (2011) *'The Ministerial Advisory Group on Dementia Research: Towards Greater Collaboration'*

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 actions⁶.

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.

⁶ <http://www.involve.org.uk/the-deficit-model-of-public-engagement-is-alive-and-well/>

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](#).

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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.

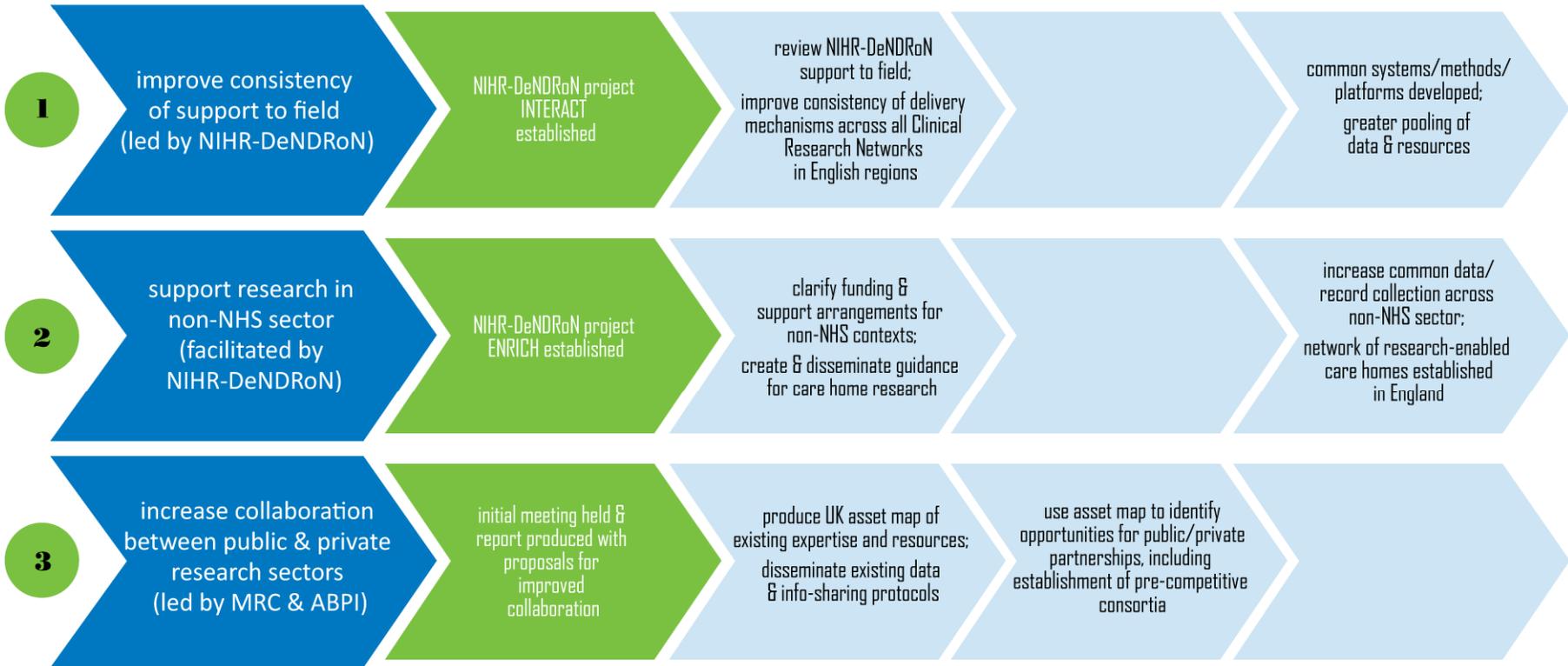
Ministerial Advisory Group:

Route Map for Dementia Research



[green = delivered]

Strengthen Collaboration and Coordination

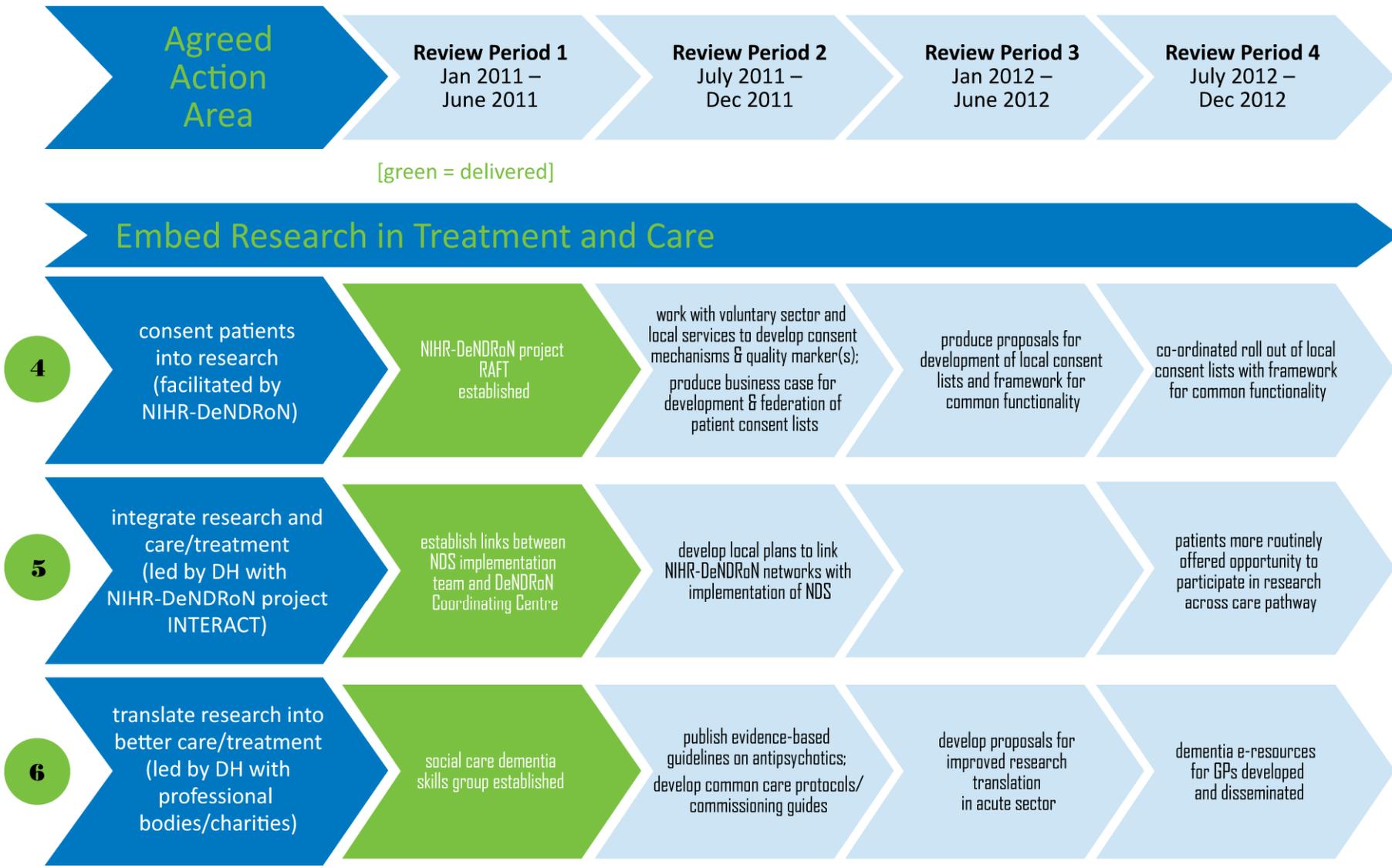


NIHR = National Institute for Health Research
 DeNDRoN = Dementia and Neurodegenerative Diseases Network
 ENRICH = Enabling Research in Care Homes

ABPI = Association of the British Pharmaceutical Industry
 INTERACT = Integrating Networks and Embedding Research in Clinical Practice
 MRC = Medical Research Council

Ministerial Advisory Group:

Route Map for Dementia Research

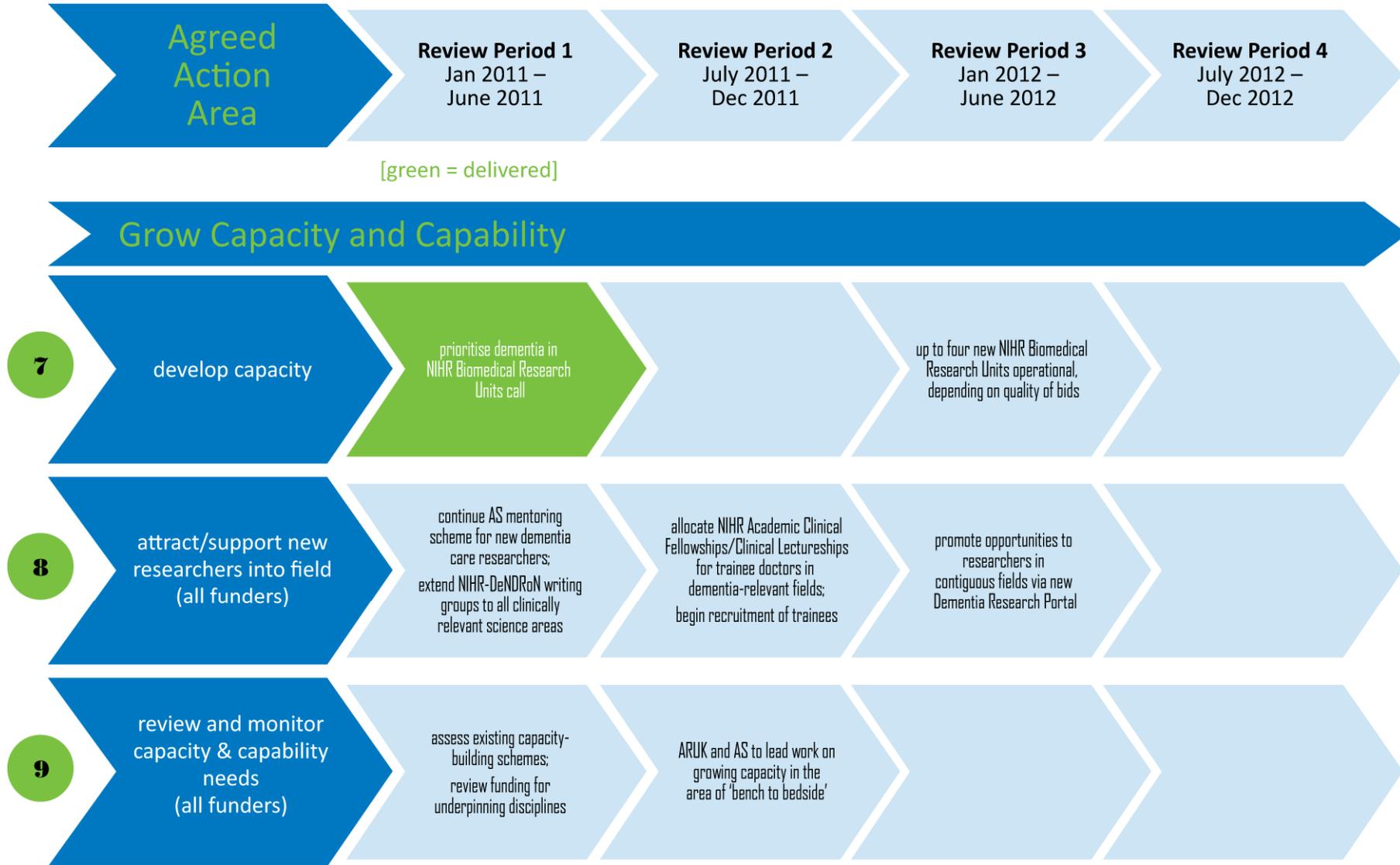


RAFT = Recruitment and Feasibility Tools

NDS = National Dementia Strategy

Ministerial Advisory Group:

Route Map for Dementia Research

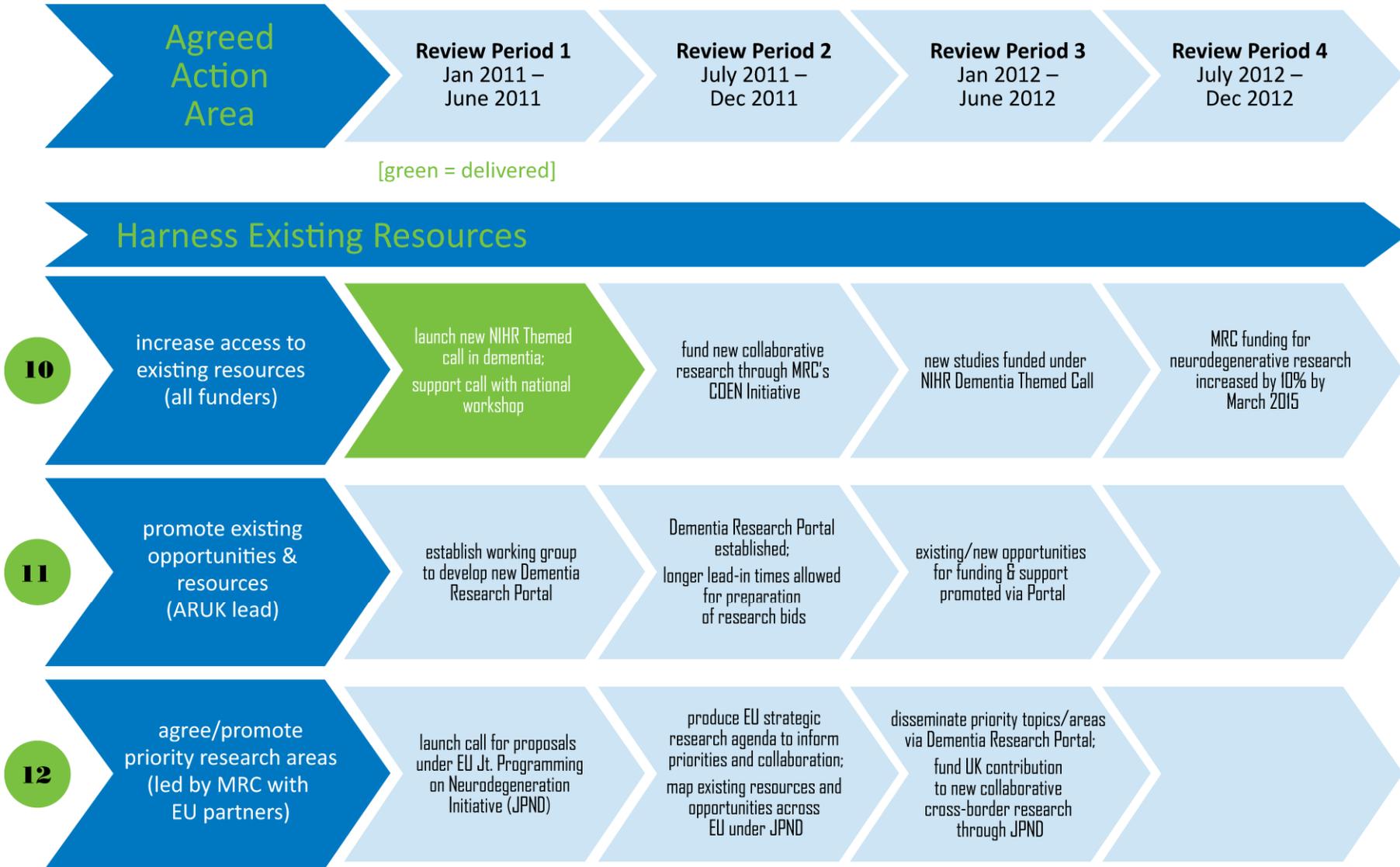


AS = Alzheimer's Society

ARUK = Alzheimer's Research UK

Ministerial Advisory Group:

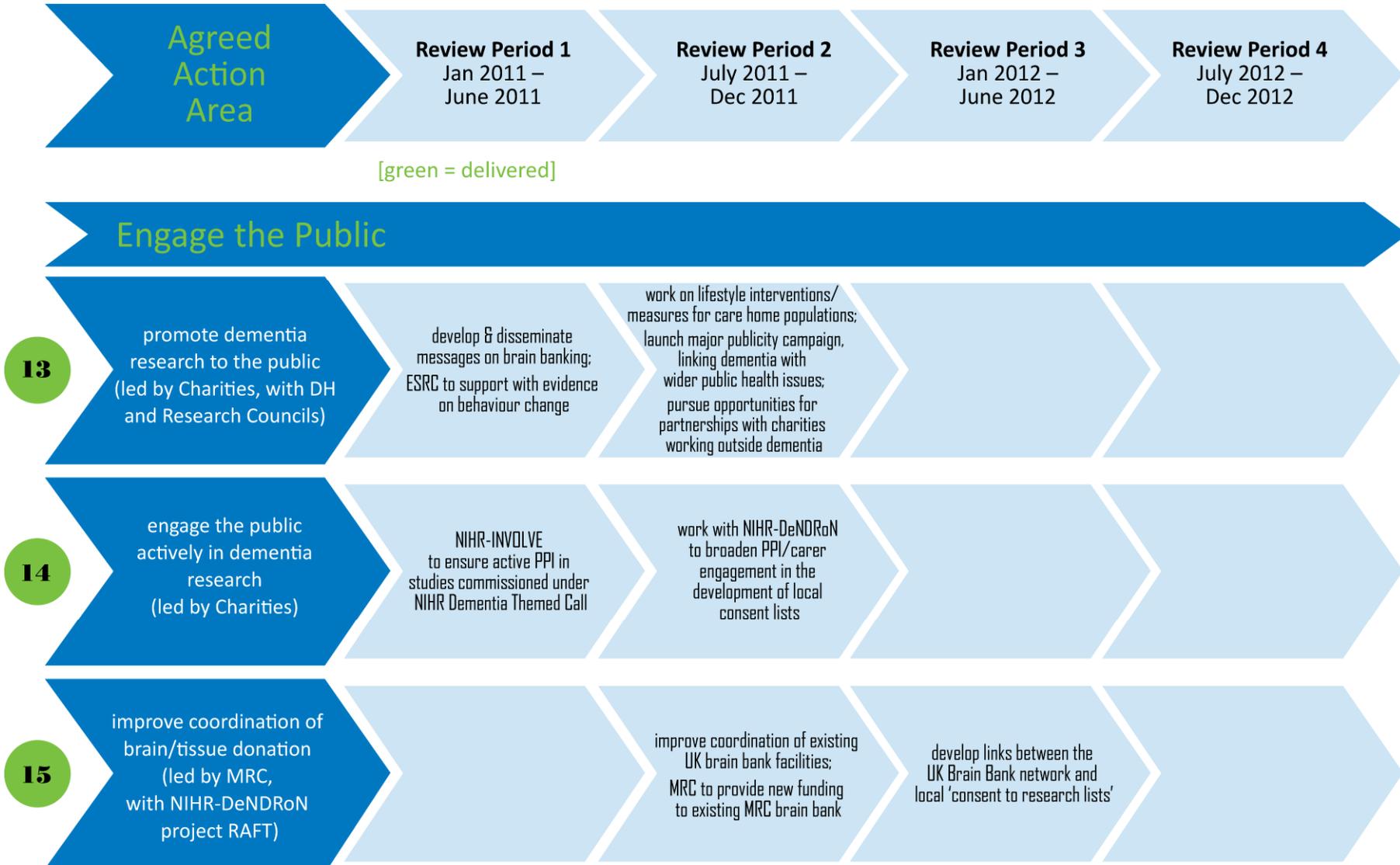
Route Map for Dementia Research



COEN = Centres of Excellence in Neurodegeneration

Ministerial Advisory Group:

Route Map for Dementia Research



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 Rossor	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**

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

Subgroup 2: Engaging the Public

Rebecca Wood (Joint Chair)	Alzheimer's Research UK
Prof Clive Ballard (Joint Chair)	Alzheimer's Society
Steve Ford	Parkinson's UK
Prof James Goodwin	AGE UK
Joe Korner	The Stroke Association
Dr Craig Ritchie	Imperial College London
Prof John Starr	Scottish Dementia Clinical Research Network

Subgroup 3: Accessing existing funding and support

Dr David Cox (Chair)	NIHR
Dr Kieran Breen	Parkinson's UK
Dr Rob Buckle	MRC
Dr Shewly Choudhury	Wellcome Trust
Jim Jackson (deceased)	Alzheimer's Scotland
Dr Hilary Lapsley	Scottish Government, Health Directorate
Prof Simon Lovestone	King's College London
Beverly Luchmun	Welsh Office R&D for Health & Social Care
Prof John O'Brien	NIHR DeNDRoN
Prof Martin Rossor	NIHR DeNDRoN
Jo Swinhoe	Alzheimer's Society
Dr John Wilkinson	Department of Health
Prof Julie Williams	Cardiff University Neuroscience Centre
Rebecca Wood	Alzheimer's Research UK

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)



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