

## TERMS OF REFERENCE

### THE FUTURE OF DEMENTIA ADVISORY GROUP

#### Purpose

In March 2012, the Prime Minister published his challenge on dementia setting out a number of key commitments to deliver major improvements in dementia care and research by 2015. The Department of Health now needs to consider the next phase of work on Dementia, post the Prime Minister's Challenge on Dementia, which is due to end in March 2015. The key focus for this work will be to set out the ambition for the outcomes we want to achieve for people with dementia and carers<sup>1</sup>, how we tackle remaining barriers and drive further improvements.

The Advisory Group will provide advice to the Department of Health to help inform the Department's work to shape the future direction of domestic dementia policy to 2020. This will be done on the clear understanding that the group is 'advisory' and will need to operate within some constraints, in particular a working assumption that any proposals for next steps should be cost neutral, i.e not imposing burdens or costs on the government, given that the Department of Health will be unable to mandate actions, including for the NHS, or pre-empt the next Spending Review. The work can, however set out the evidence for why a particular intervention would be beneficial including to different parts of society and other government departments (i.e cost-benefit), but without committing the government to specific spend.

What happens from 2015/16 to 2020 will be determined by the next Government in the context of the Spending Review – without committing or obligating that Government, the intention it is to set out the areas we believe it will be necessary to take sustained action on to continue to improve dementia care – focused around the **outcomes we want to achieve for people with dementia and carers.**

Once the political direction and the spending envelope are determined, this Advisory Group's work will inform the subsequent action plan for implementation.

The Department of Health Dementia Policy Team will draw on the views and expertise of stakeholders on the Advisory Group and the wider views of people with dementia, care givers and others to inform advice to Ministers.

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<sup>1</sup> Please note that where reference to 'carers' is made, this indicates 'unpaid carers' and not paid health and care professionals.

## Remit

The Advisory Group will:

- Review the evidence on progress on dementia care and support over the last five years to identify where progress has been made, key challenges and gaps and priorities for action. This will include looking at the evidence on risk reduction and how the incidence of dementia could be reduced.
- Consider what success could look like by 2020 in the following broad areas:
  - Improving the provision and continuity of personalised health and social care for people with dementia and carers - this includes risk reduction, prevention, diagnosis, post-diagnostic support, the role of technology and new models of care.
  - Promoting awareness and understanding.
  - Building social engagement by actions of individuals, communities and businesses.
  - Boosting dementia research capacity and capability, the opportunity for individuals to get involved in research and optimising knowledge transfer and pathways to impact.
  - Improving support for carers including improving their health, wellbeing and experience.
  - Cross-cutting: Supporting the education, training and development of the health and care and wider workforce.
  - Cross-cutting: Global action on dementia.
  - Cross-cutting: Ensuring equity of access, provision and experience

This will include looking at what we can learn from international evidence and experience.

## Meeting frequency

The Advisory Group will meet every 4-6 weeks, unless agreed otherwise, between October 2014 and March 2015. Meetings will normally be 2 hours in duration and held in central London with a video conference link to Leeds. Members will be advised of the date and time at the earliest opportunity ahead of each meeting. The Advisory Group may also be asked to consider documents virtually, by email.

## **Members**

The list of members is appended. Each member is asked to nominate empowered deputies where they are unable to attend in person. Notice of this substitution should be given to the secretariat ahead of meeting.

National delivery partners will be invited to attend meetings. In parallel and outside of the Advisory Group meetings, the Department of Health will continue to engage with national delivery partners to ensure that they are fully engaged and involved in the development of the vision.

## **Communication**

Papers will be circulated at least three working days before each meeting. A note of the key actions from each meeting will be agreed with the Chair and circulated within five working days of each meeting. The action notes will not be restricted documents unless otherwise marked.

## **Accountability**

The Advisory Group will be chaired by Clara Swinson, Director for Social Care Policy at the Department of Health (or where this is not possible her deputy Lorraine Jackson, Deputy Director for Dementia Domestic Policy) and will report to the Dementia Programme Board, co-chaired by Jon Rouse Director General for Social Care, Local Government and Care Partnerships and Norman Lamb, Minister of State for Care and Support.

## **Membership**

### **Chair**

Clara Swinson, Department of Health

Lorraine Jackson (Deputy), Department of Health

### **Members**

Jeremy Hughes, Alzheimer's Society

Tom Wright, Age UK

Helena Herklots, Carers UK

Bruce Bovill, Carer

Joy Watson and Tony Watson, person living with dementia and carer

Graeme Whippy, Lloyds Banking Group (representative from the PM Challenge Dementia Friendly Communities Champion Group)

Sarah Pickup, Hertfordshire County Council (representative from the PM Challenge Health and Care Champion Group)

Martin Rossor, UCL (representative from the PM Challenge Research Champion Group)

Paul Lincoln, UK Health Forum

Helen Kay, The Local Government Association

David Pearson, The Association of Directors of Adult Social Services

Hilda Hayo, Chief Executive of Dementia UK

Graham Stokes, Chair of Dementia Action Alliance

Dawn Brooker, The University of Worcester

Martin Knapp, London School of Economics

Tim Parry, Alzheimer's Research UK

Simon Chapman, National Council for Palliative Care

Jill Rasmussen, Royal College of General Practitioners Dementia Champions

Martin Green, Care England

Bridget Warr, UK Home Care Association