

## 1. 'Join dementia research' media briefing

### What are we launching today?

'Join dementia research' is an innovative new national service designed to help people register their interest in volunteering for dementia research studies, to make a real difference for those affected by the condition and their families.

### What do we want people to do?

Sign up to 'Join dementia research' to show they are interested in taking part in research. The service is aimed at people with dementia and their carers, but anyone with and without dementia over the age of 18 can sign up and people can register on behalf of someone else.

### Key messages to get across in a media interview:

1. We need more people with dementia to take part in research to help us accelerate progress towards better dementia care and ultimately a cure for the condition. Currently less than 5% of people with dementia take part in research.
2. Join dementia research has been set up by National Institute for Health Research (NIHR), Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society, and has been funded by the Department of Health to empower more people to take part in dementia research.
3. It's really easy to sign up and help us make a real difference for people affected by dementia and their families. Sign up online at the Join dementia research website [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk) or call one of the charity helplines and they will guide you through the registration process.

Additional information for longer interviews:

### What happens once you sign up?

- To sign up you provide some basic health information about the person you are registering.
- Researchers can use this information to find people who are suitable for their studies.
- If you match a study then you decide on a case-by-case basis which studies you would like to take part in.

- If you agree to take part in a study but later change your mind, you can opt out without giving a reason.

### **Why should people sign up?**

- There are currently only a small number of treatments available that reduce the symptoms of dementia, but there are no treatments that slow the underlying disease progression.
- Research is essential to prevent dementia, find treatments, discover potential cures, and improve the lives of everyone living with the condition.
- By signing up to take part in dementia studies, people can help to accelerate our progress in all of these areas.

### **What kinds of studies might someone take part in?**

- There is a wide range of research studies on Join dementia research, ranging from clinical trials of new treatments, to surveys with carers about their quality of life, to studies of healthy people in middle age.
- Not everyone who signs up to Join dementia research will be able to take part in a study but signing up is the best way that people can support dementia research.