

GOVCONNECT

Dementia 2020

NHS

*National Institute for
Health Research*

Meeting the dementia challenge through research

Dementia 2020

Transforming Care, Support & Research

12th of April 2016

Church House, London



Professor Martin Rossor

NIHR National Director for Dementia Research

G8 Dementia Summit Commitments



- identify a cure, or a disease-modifying therapy, for dementia by 2025
- significantly increase the amount spent on dementia research
- increase the number of people involved in clinical trials and studies on dementia
- establish a new global envoy for dementia innovation
- develop an international action plan for research
- share information & data from dementia research studies to work together & get the best return on investment in research
- encourage open access to all publicly-funded dementia research to make data & results available for further research as quickly as possible

Better research



World leading, major programmes of research and significant investment in infrastructure.

Expansion of the dementia research workforce.

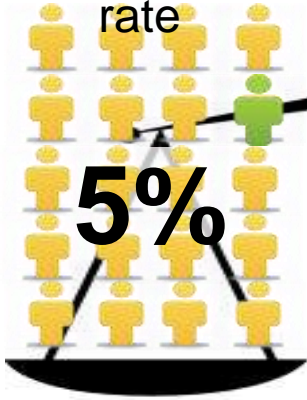
Greater participation of people with dementia in research:

- 25% of people diagnosed with dementia registered on Join Dementia Research
- 10% participating in research, up from the current baseline of 4.5%

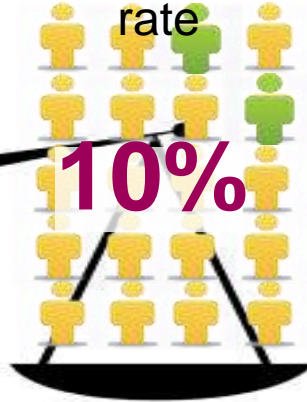
Increased research in care homes.

But...

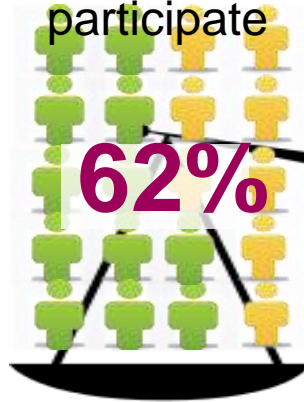
Current participation rate



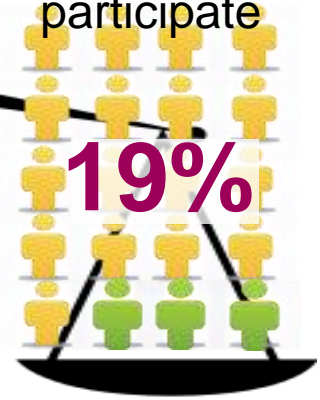
2020 target participation rate



Public willingness to participate



Public knowledge about how to participate





Welcome to 'Join dementia research', a place to register your interest in participating in dementia research.

Dementia affects 850,000 people in the UK.

The only way to beat the condition is through research.

Help us beat dementia

Anyone, with or without dementia, can register as a volunteer or [sign-up for someone](#) providing that you have their consent.

[Signing up](#) is the first step in becoming involved in supporting vital research studies across the nation.

[Sign up for me >](#)

[Sign up for someone else >](#)



[> Sign up](#)

[> Sign up for someone else](#)

If you already have an account please [login](#).

Join dementia research - the numbers so far...

17,135 Volunteers

4,921 Volunteers Enrolled in Dementia Studies

115 NHS, University & Commercial Research organisations

566 Trained Researchers

62 Research studies



Increases public awareness



2/3rds of people willing to take part in research

Fewer than 1 in 5 know how to find out about it



Directly via internet



Through charity helplines



Through NHS memory clinics



Improves use of data

Aggregates & structures data about patients & their consent



Aggregates & structures data about research studies



Matches patients to studies



Enables researchers to contact patients



The story so far - volunteers

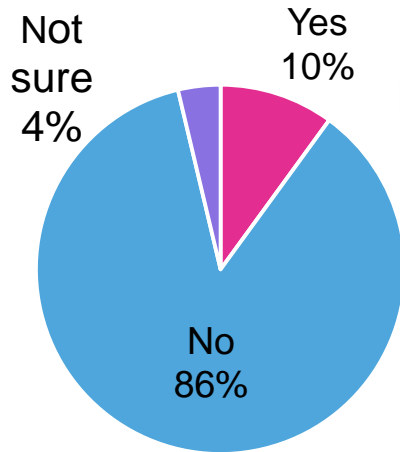


15,330
total volunteers

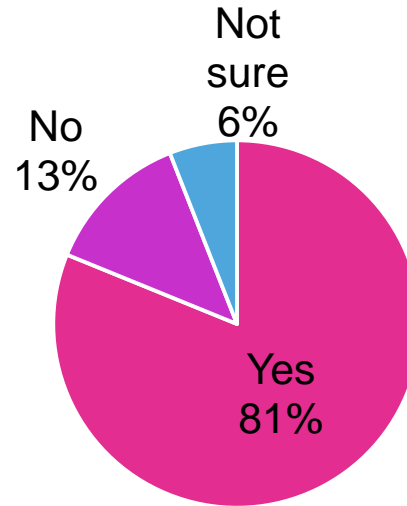


Is this making a difference to volunteers?

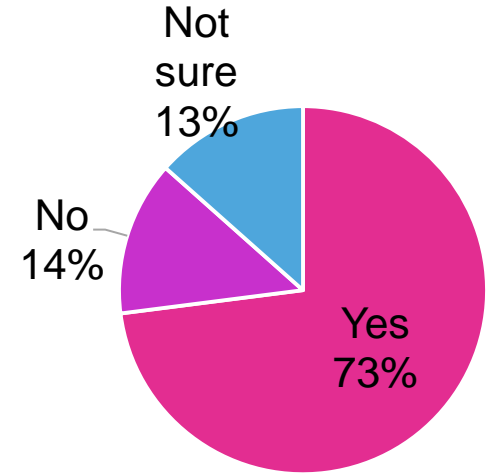
Know how to get involved?



Has JDR increased awareness?

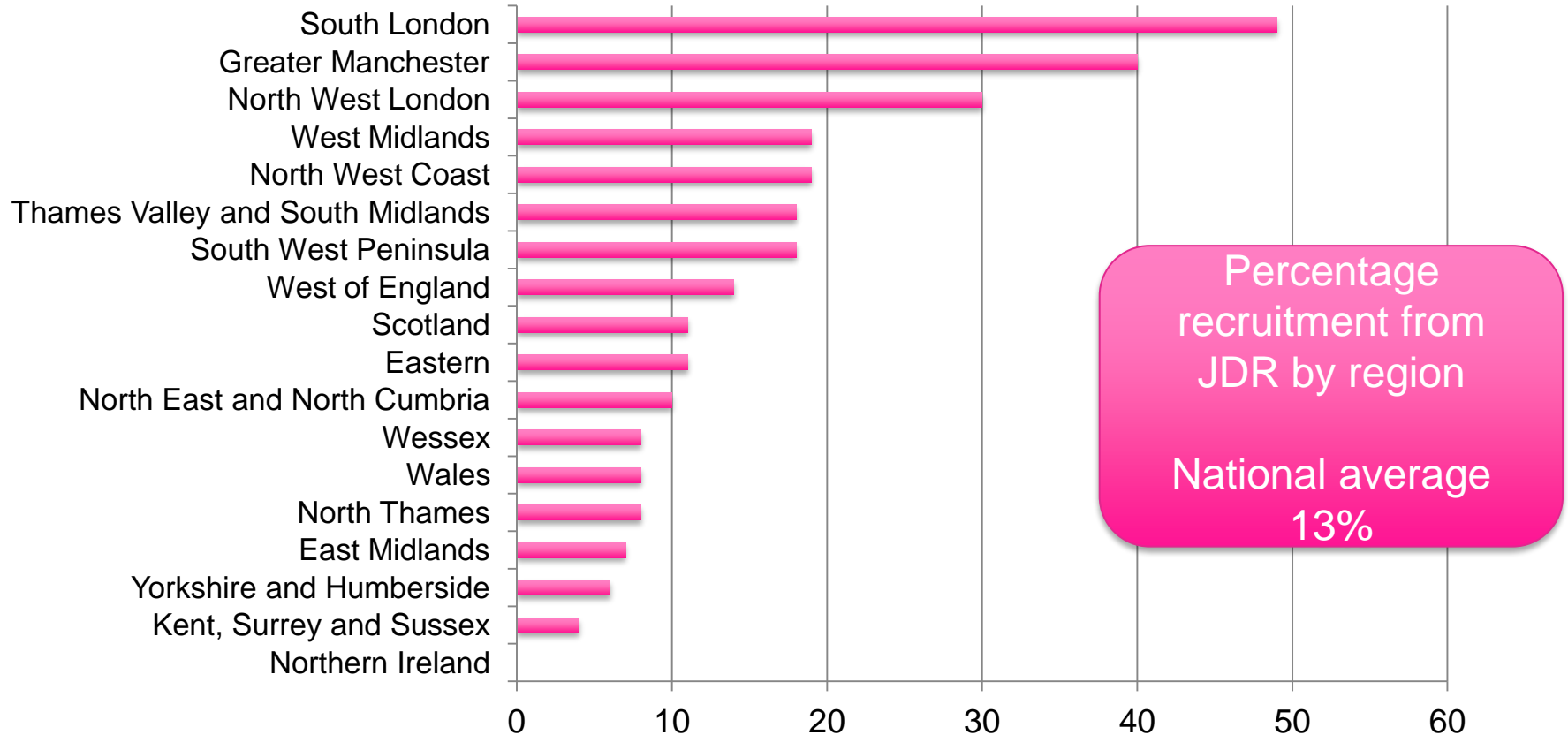


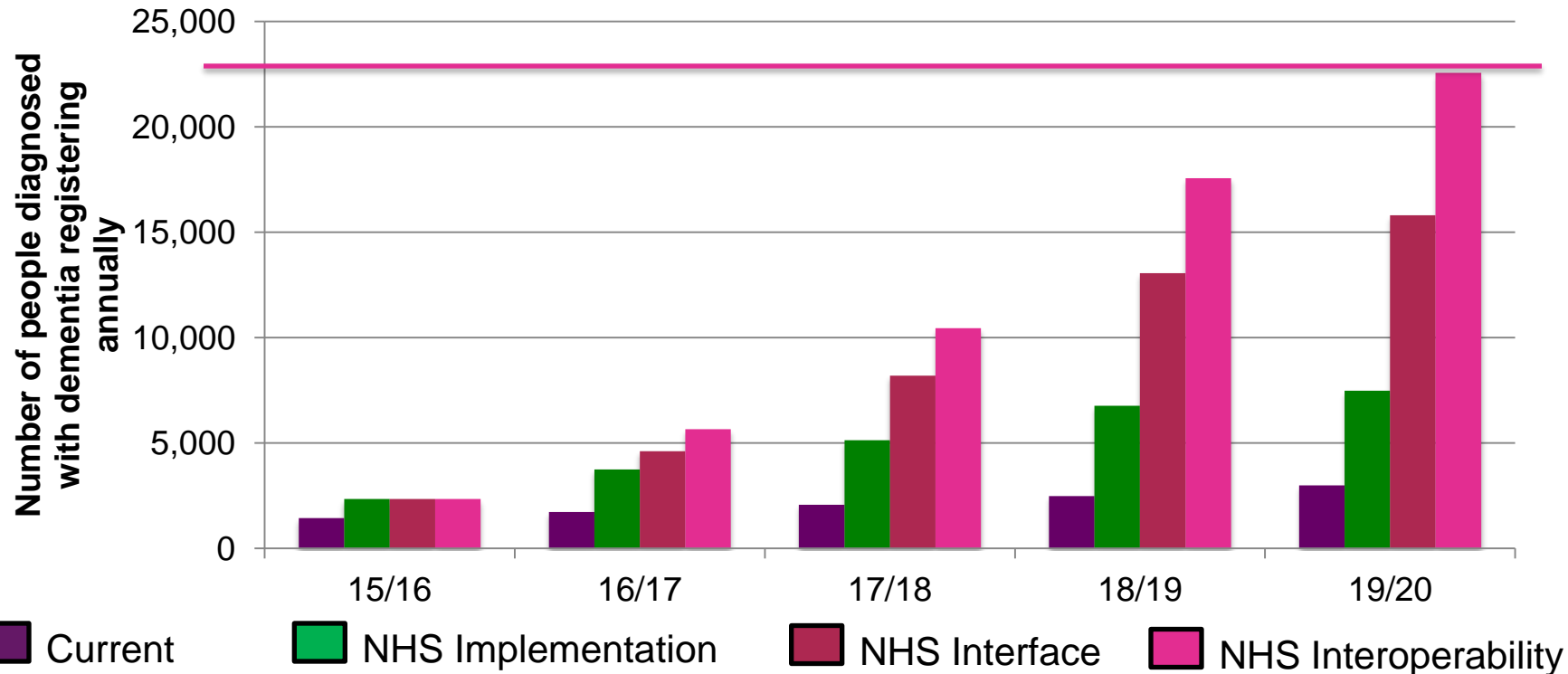
JDR has made it easier to take part?



4479 people surveyed – 705 responses (15.7%)

Is this making a difference to researchers?





People affected by dementia value
being involved in research

SUPPORT



Your population
want to be
involved in
research

RESEARCH

CARE

Research has direct individual
and population-level benefits

NIHR Dissemination Centre: highlight on research on carers

NHS

*National Institute for
Health Research*

NIHR Dissemination Centre

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[Home](#) » [Highlights and reviews](#) » Supporting Carers of People with Dementia Highlight



Supporting carers of people with dementia highlight

Dementia is becoming more common as we live longer. Caring for people with dementia is demanding, with increased dependency as the disease progresses and behaviour which is often challenging. Around two thirds of people with dementia live at home and there may be as many as 670,000 people in the UK who are the main carers for people with dementia.

Discover the latest research

Explore NIHR Signals and other publications

[Take me there](#)

Become a rater

Find out more about becoming a rater, what's involved, and register your interest

[Tell me more](#)

Keep in touch

For regular Signals and occasional updates

<http://www.dc.nihr.ac.uk/highlights-and-reviews/supporting-carers-of-people-with-dementia>

A TOOLKIT FOR CARE HOME RESEARCH



RESEARCH COMMUNITY



Advice and guidance for researchers, research staff, and local research networks on how to prepare and carry out studies in a care home.



CARE HOME STAFF



Find out what it means to support research in a care home, and what the benefits are for you in participating in research studies.



RESIDENTS, FAMILY & PUBLIC



Learn about the role residents, family members and friends can play in supporting high-quality research.

www.enrich.nihr.ac.uk

The ENRICH toolkit is a resource to support researchers, care home staff, residents & relatives deliver research in care homes.

DEMENTIA

An iceberg floating in a blue ocean under a blue sky with light clouds. The tip of the iceberg is above the water line, while the much larger base is submerged. The water is a deep blue, and the sky is a lighter blue. The iceberg is white and blue, with some internal textures visible. The text is overlaid on the image.

Mild Cognitive
Impairment
MCI

Premanifest disease

Early progressive
disease