

Dementia 2020
30 April 2019

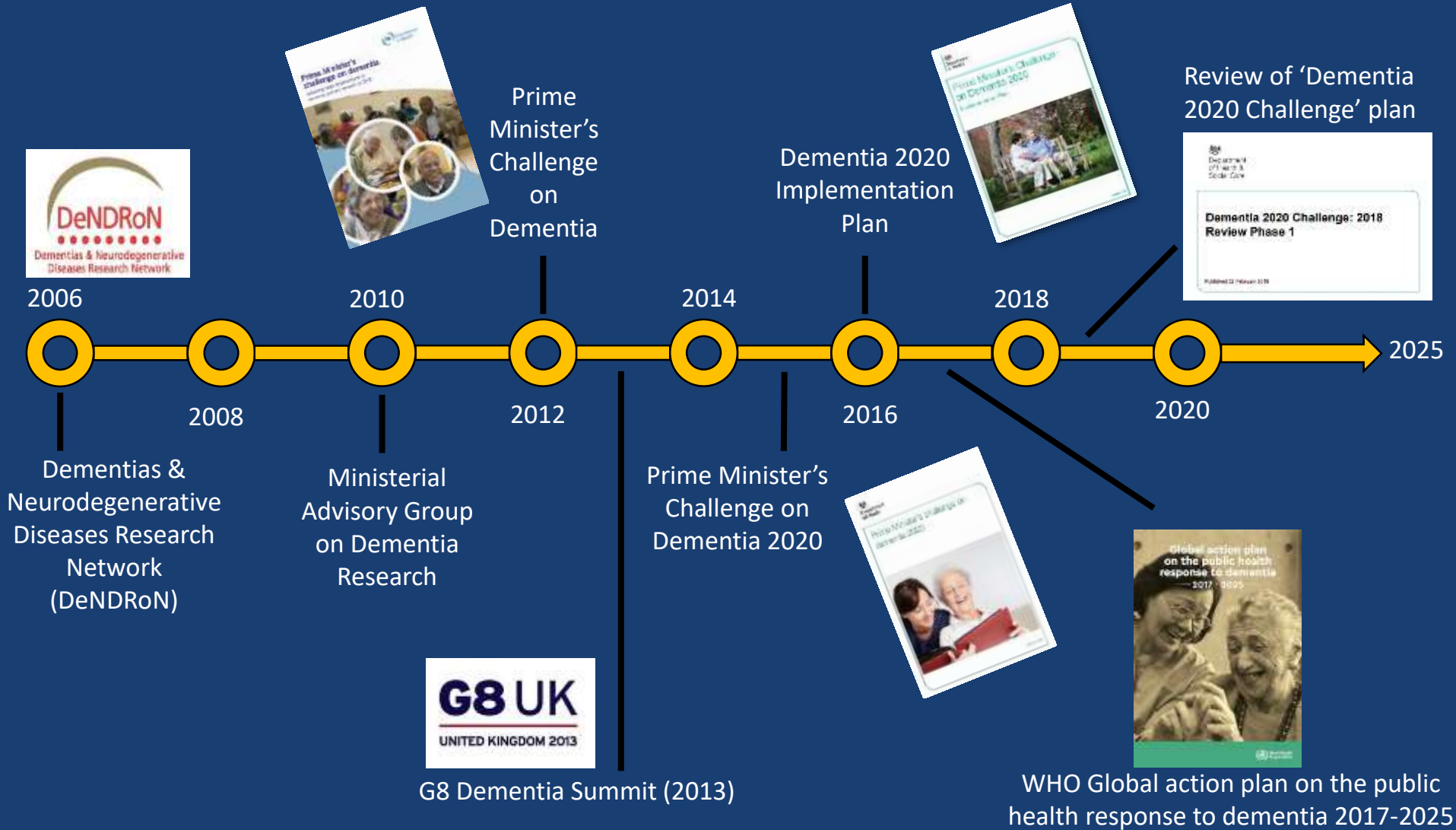


Looking to 2025: Creating the Research Environment

Martin Rossor
National Director for Dementia Research



Dementia Research Policy Timeline in the UK



Increased funding for dementia research

To make best use of the increased funding for dementia research, we will need to:



attract new and young researchers



support informed choice for research participation

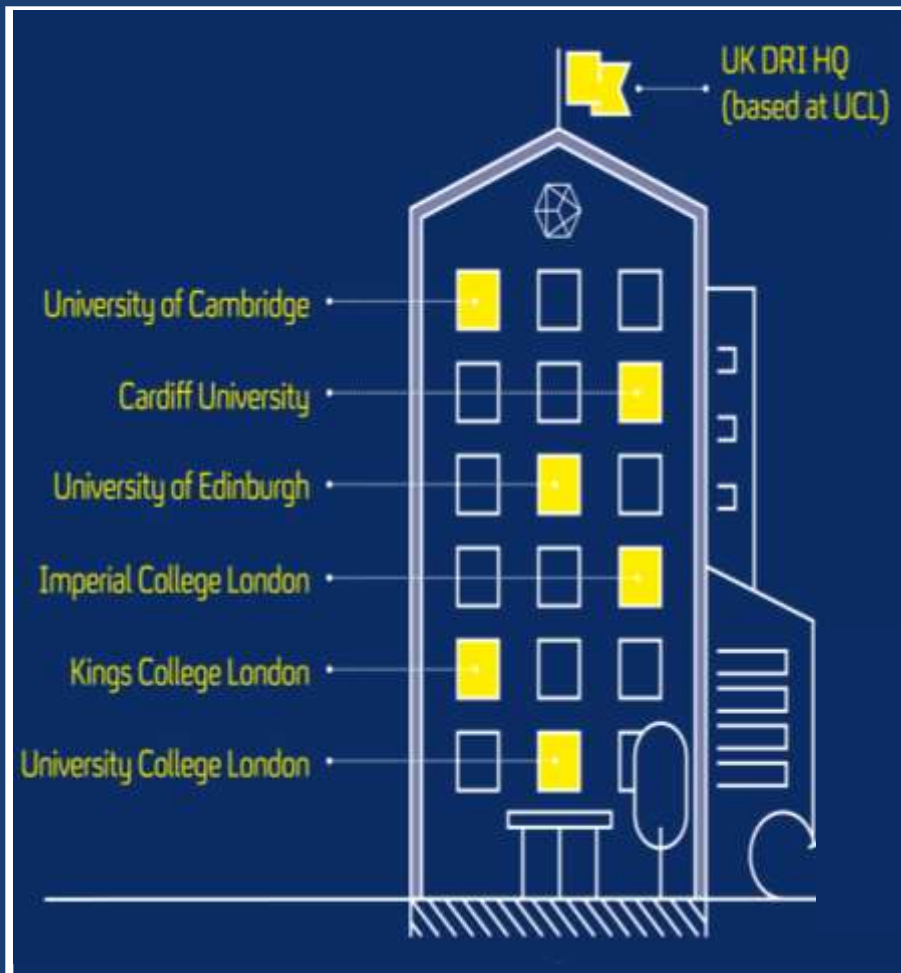


ensure robust public and patient involvement

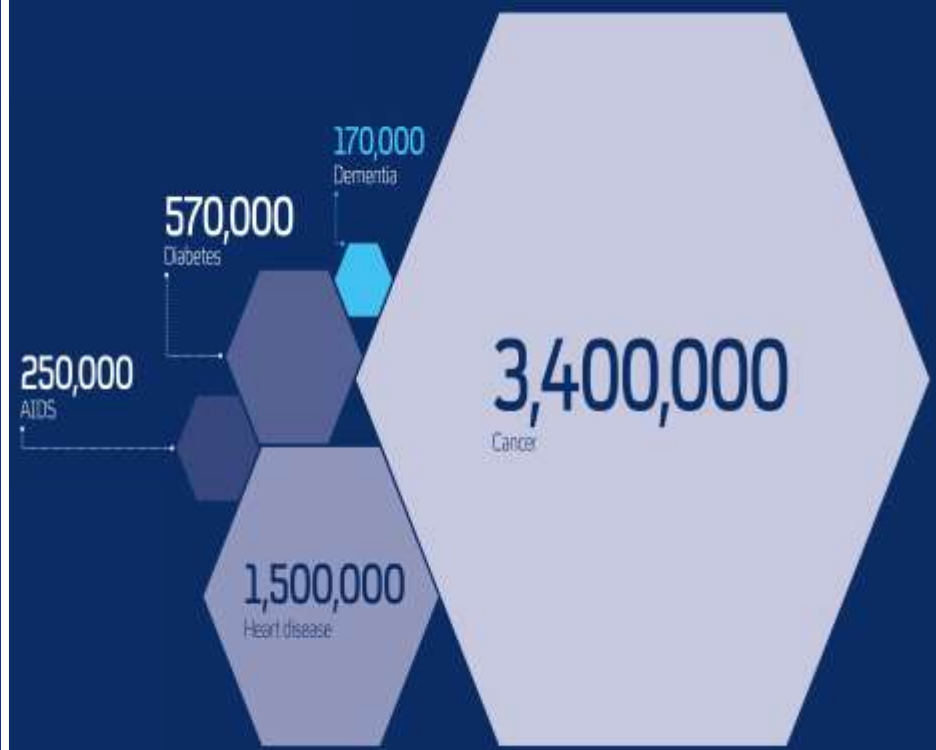
Attract new and young researchers

UK Dementia Research Institute

Defined by close collaboration : Working closely with dementia initiatives, brain banks, charities, UK research, and international industry



Filling in the knowledge gap



Comparison of number of publications on PubMed

Attract new and young researchers

The screenshot shows the homepage of the Dementia Researcher website. At the top left is the logo for 'DEMENTIA RESEARCHER' with the tagline 'A network for early career researchers'. To the right is the 'National Institute for Health Research' logo and a 'Log in / Sign up' button. A navigation menu includes 'About', 'Jobs', 'Forum', 'Funding', 'News', 'Events', and 'Contact'. A search bar is located on the right. The main content area features a large image of a scientist in a lab coat looking through a microscope. Below this image is the heading 'We can help Early Career Researchers like you by:' followed by a numbered list of four benefits: 1. Connecting you with your peers, 2. Providing a platform to share your ideas, 3. Offering career support and opportunities, and 4. Ensuring easy access to continued learning. A 'Sign up now for free' button is positioned below the list. At the bottom left, there is a 'CONNECT' section with an image of people in a meeting and the text 'Engage with your peers through our discussion forums' and a 'Sign up here' button. At the bottom right, there is a 'SEARCH' section with a search bar, a dropdown menu for 'Organisation', and a text input for 'Field of research', with a 'Search documents' button below.

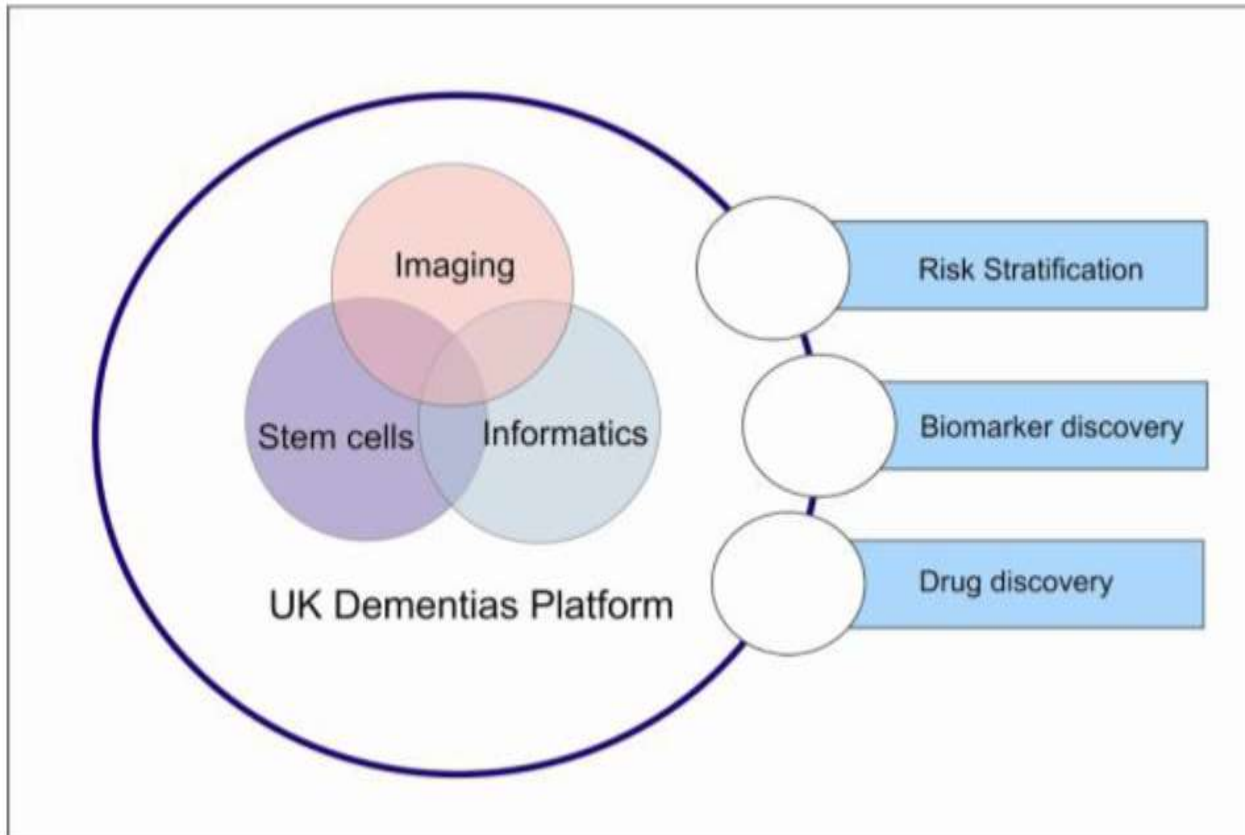
- Find a collaborator
- Find funding / job opportunities
- Find supporting tools and resources
- Peer support
- Share / find sample protocols
- Find events
- Share their work
- Ask an expert
- Find information on development opportunities
- Network with colleagues
- Journal club
- Access podcasts / webinars
- Get research ideas
- Get support not provided by smaller institutions

<https://www.dementiaresearcher.nihr.ac.uk/>



Dementias Platform^{UK}

Medical Research Council



DPUK

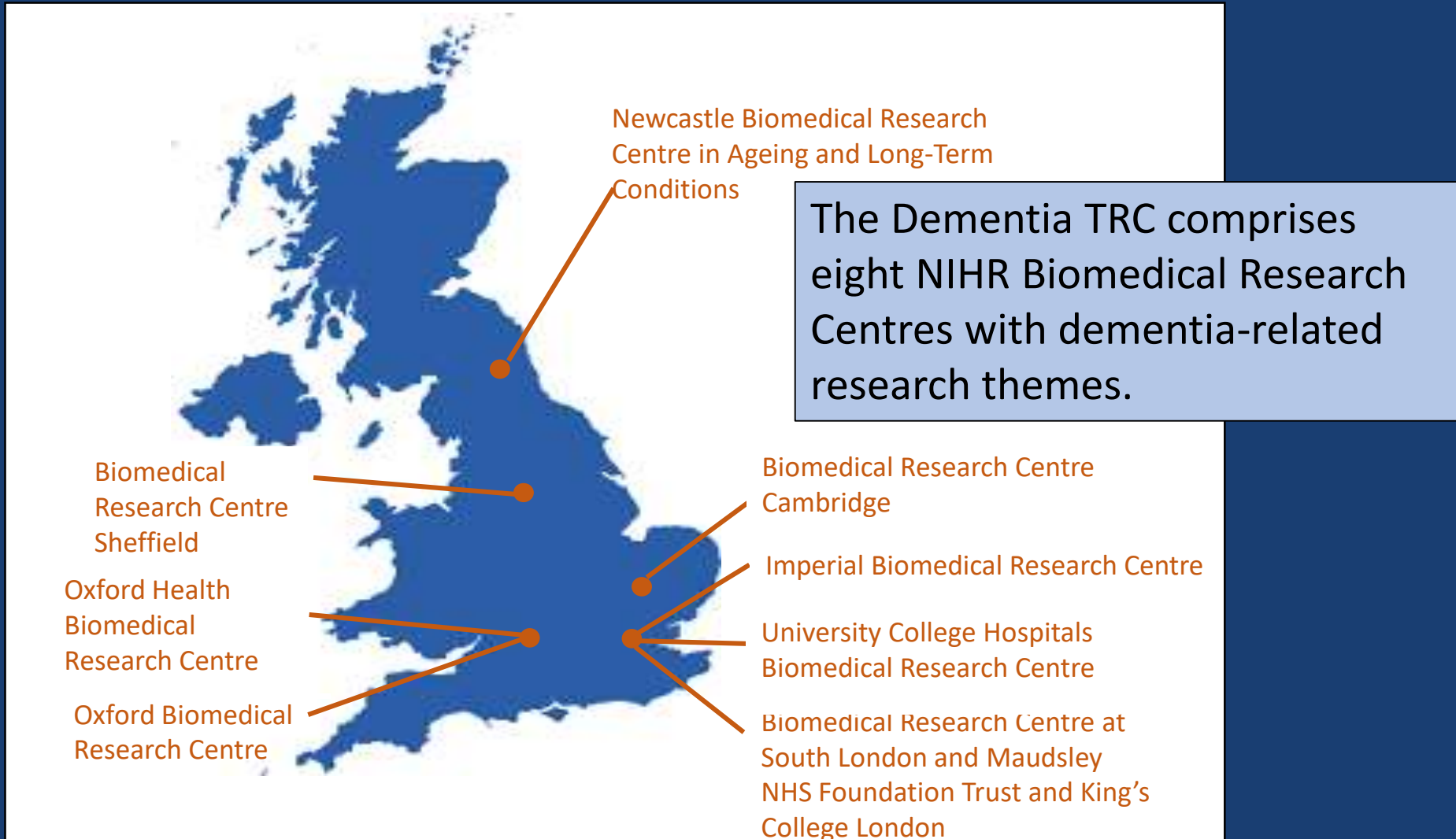
52 applicants

11 Universities

£41m for capital

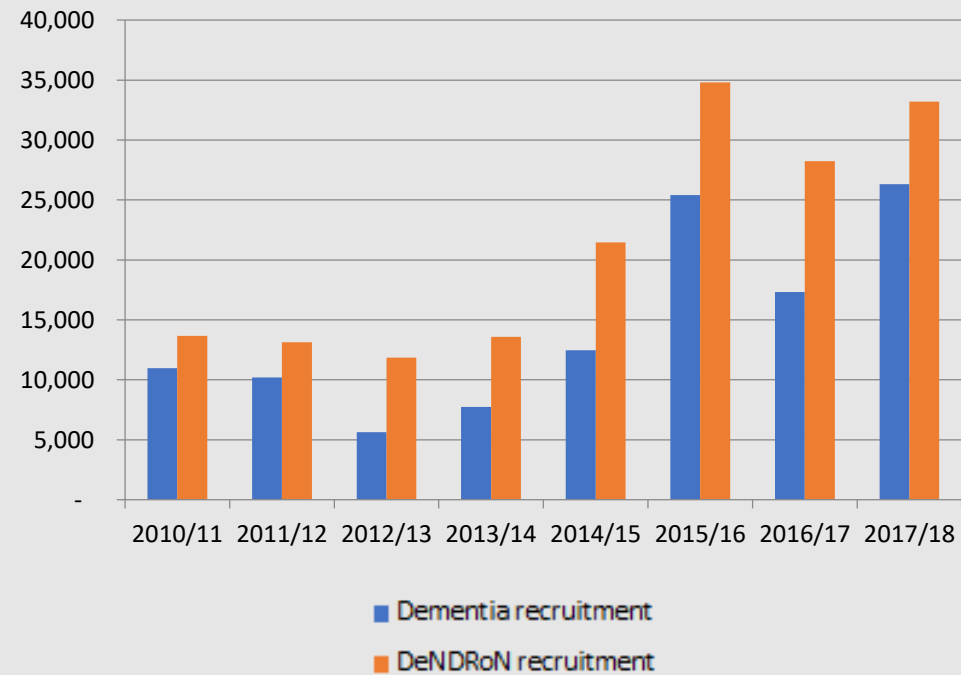
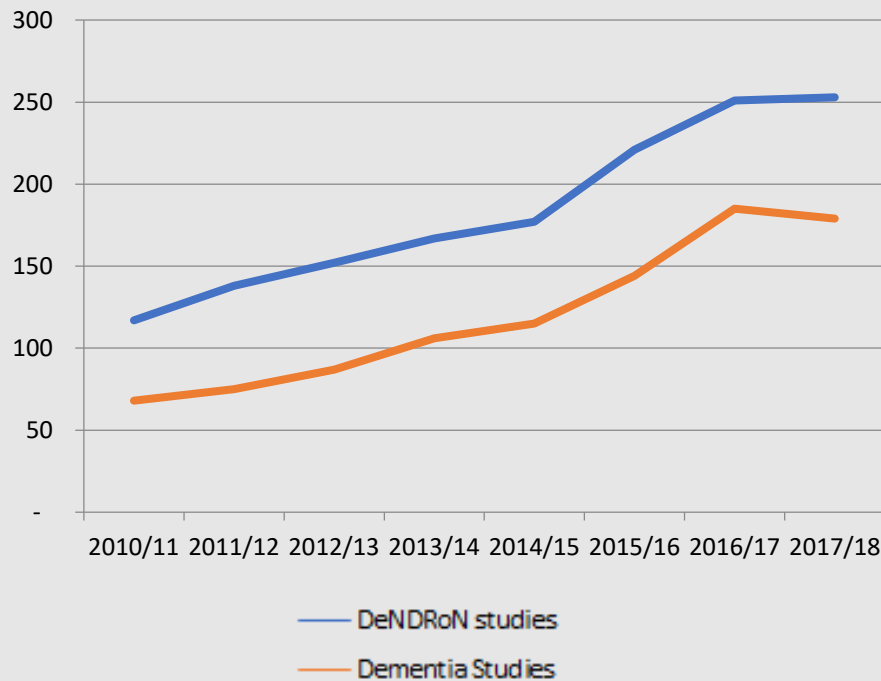
Funded Sept 2014

Dementia Translational Research Collaboration (D-TRC)



Delivering Clinical Research: Dementias and Neurodegenerative Diseases Research Network (DeNDRoN)

Full national coverage from 15 Local Clinical Research Networks covering the whole of England (+ dementia networks in the devolved nations)



The ENRICH network

- Networks exist across all England and Scotland with almost 1000 care homes participating, providing care to over 50,000 people
- Local networks are supplemented by national agreements with corporate partners such as BUPA / OSJCT / CIC / Amore proving early national coverage
- More corporate partners are being sought



Join Dementia Research

An online and telephone service that helps patients and the public find and take part in dementia research studies

Supporting delivery of Government's Challenge on Dementia 2020

The screenshot shows the homepage of the 'Join dementia research' website. At the top, there is a navigation bar with links for 'Home', 'About the service', 'How it works', 'Why sign up?', 'Any questions?', and 'For professionals'. The main header features the 'Join dementia research' logo on the left and the 'NHS National Institute for Health Research' logo on the right. A central banner image shows a woman looking at a laptop with the text 'WHO CAN HELP RESEARCHERS TO BEAT DEMENTIA?' and 'YOU'. To the right of the banner is a large pink graphic with the text 'SIGN UP TODAY'. Below the banner, there is a section titled 'Welcome to 'Join dementia research', a place to register your interest in participating in dementia studies.' followed by a paragraph explaining that anyone can register as a volunteer. Below this is another paragraph stating that the service is currently being tested and only includes research studies from the North London area. At the bottom, there are two columns: 'What's new' and 'Your stories'. On the right side, there are two buttons: 'Sign up' and 'Sign up for someone else', and a link for 'login' if the user already has an account. A 'Key things you should know about the service' section is also present at the bottom right, listing three points: 'Sign up today', 'Answer as many of the questions as you can', and 'View the studies you match to'.

Directly connecting volunteers and researchers

Join dementia research National Institute for Health Research

Home About the service How it works Why sign up? Any questions? For professionals- News & Info

Welcome to your 'Volunteer Summary' page.
You can update or edit your own volunteer information here, or create a volunteer information record for someone else.
To increase the chances of being contacted with an opportunity to take part in a study, please click on 'Update/ Add information' and answer some additional questions about the volunteer. The more we know about the volunteer, the better we are able to match them with suitable studies.

Volunteer **Potential Study Matches**

An Example (Me)
Date of Birth: 23/01/1914
Address: National Hospital For Neurology & Neurosurgery, WC1N 3BG
Update / Add information
Additional Questions
Register a profile for someone else

If you would like to express interest in a study then check the box. Note that this is not required and you may be contacted about other studies.

Study	Start Date	End Date	Interested?
SPARK SBRI demo	12/10/2015	31/10/2016	<input type="checkbox"/>
Empty study	16/01/2016	21/01/2016	<input type="checkbox"/>
Dementia and Dance	21/07/2014	21/07/2015	<input type="checkbox"/>
Healthy study	03/10/2002	15/10/2015	<input type="checkbox"/>

Does Aspirin reduce cognitive decline in people with early AD who are on Aricept? **CANCELLED** **OPEN**

Publishing Threshold - 80% [Change Threshold](#)

NAME	DISTANCE	AGE	INTEREST	MATCH	STATUS
Mrs Jane McCarthy	N/A	57	N/A	63%	<input type="button" value="PUBLISH"/>
Mrs Julia Johns	11.56	57	N/A	63%	<input type="button" value="PUBLISH"/>
Mr Christian Jamason	8.88	61	N/A	100%	<input type="button" value="UNPUBLISH"/>
Mr Dawson	8.88	61	Very Interested	100%	<input type="button" value="UNPUBLISH"/>
Mrs Julie Pullen	9.42	61	N/A	100%	<input type="button" value="UNPUBLISH"/>
Mrs Shaw	8.88	61	N/A	100%	<input type="button" value="UNPUBLISH"/>
Mr Alan Jamason	8.88	61	N/A	88%	<input type="button" value="UNPUBLISH"/>

Growth since implementation in 2015

Join Dementia Research in numbers



916

trained researchers
using the service



253

NHS, University & commercial
sites have used the system



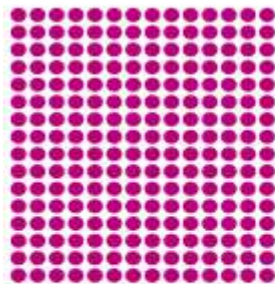
102

studies open to
recruitment



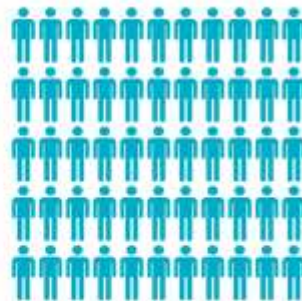
29%

of volunteers have
participated in a study



80,779

volunteers screened
for studies



40,286

total volunteers



371

studies have recruited



12,881

participants enrolled
in studies to date

Support informed choice for research participation

NIHR | National Institute
for Health Research

UK Dementia Research Recruitment Registers workshop

January 9th 2019

Summary:

1. People joining registers should have access to information about the ways in which they can contribute to research, including information about all relevant research opportunities open to them through the 'family' of registers, and be able to make an informed choice about what to participate in.
2. Researchers should be able to access registers as openly as possible to facilitate the conduct of academic and industry research as quickly and cost-effectively as possible.

**Join
dementia
research**



**Dementias
Platform^{UK}**
Medical Research Council

EPAD

European Prevention of
Alzheimer's Dementia Consortium



**Scottish
Brain
Health
Register**



**CRIS
NETWORK**

PROTECT

NIHR BioResource

Bringing people together and leading research

Ensure robust public and patient involvement

Increase engagement opportunities

Public Patient Involvement

Citizen Science

Research champions



Feasibility assessment

Knowledge transfer

Develop volunteers into a community

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