The South West Peninsula Regional Research Delivery Network (SWP RRDN)

Community Engagement

'Join Dementia Research'

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Research Engagement and Inclusion Team



RDN regions

We cover the whole of England and consist of 12 Regional Research Delivery Networks (RRDNs) and a coordinating centre (RDNCC), working together as one.







The last 10 years

From 2014 - 2024, the NIHR Clinical Research Network South West Peninsula (CRN SWP) enabled our health and care organisations, our staff and our population to have access to research opportunities across Cornwall, Devon and Somerset.

This research supported improvements in health and care and gave access to cutting edge treatments for our population.

The CRN SWP, in partnership with delivery organisations and healthcare professionals across the region, gave more than 300,000 people the chance to participate in nearly 3,000 portfolio studies.

That's over 10% of the total regional population, or put another way, enough people to fill Exeter's Sandy Park Stadium 20 times over.





335,219 participants recruited





firsts

0

93% of participants would take part in research again



Chief Investigator studies setup and delivered



commercial studies supported and recruited to



46,130
participants recruited into primary care research



5,718
people completed the Participant in Research Experience Survey
(PRES)



participants recruited into 159 non-NHS studies



participants recruited into COVID-19

studies

COVID-19 studies delivered



1,355

participants recruited across 104 research active schools to 7 studies



1,015

participants recruited across 114 research active care homes to 16 studies



69

participants recruited across 4 research active hospices to 4 studies



participants recruited across 41 research active dental practices to 8 studies



20,814

participants recruited into commercial studies



118

commercial Chief Investigator studies



UK firsts, 3 European firsts and 9 global firsts



5,718

people completed the Participant in Research **Experience Survey**



34,000

participants recruited into dementia and neurodegeneration studies



13,000

participants recruited into diabetes studies



17,000

participants recruited into cancer studies



17,000

participants recruited into cardiovascular studies

Specialties

Ageing

Anaesthesia, Perioperative Medicine and Pain Management

Cancer

Cardiovascular

Children

Critical Care

Dementia and Neurodegeneration

Dermatology

Diabetes, Metabolic and Endocrine

Ear, Nose and Throat

Gastroenterology and Hepatology

General Practice

Haematology

Imaging

Infection

Mental Health

Musculoskeletal and Orthopaedics

Neurological disorders

Ophthalmology

Oral and Dental

Palliative Care

Public Health

Renal

Reproductive Health and Childbirth

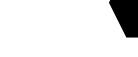
Respiratory

Social Care

Stroke

Surgery

Trauma and Emergency Care



Stroke



Cardiovascular







Mental health



RDN research engagement and inclusion priorities

- Ensure the public has access to relevant and appropriate information and options to engage in research, including but not limited to, Be Part of Research and Join Dementia Research.
- Create a public partner community, supported regionally with a cross-NIHR remit and standardised national ways of working, and reaching across a broad and diverse range of communities
- Develop capacity and capability to deliver an inclusive and diverse portfolio of studies
- Work with community partners to build trust in under-represented communities and promote research opportunities relevant and required in those communities







Join Dementia Research



Join Dementia Research



- Join Dementia Research is a nationwide service that enables anyone over 18 to register their interest in dementia research.
- Since its inception in 2015, over 50,000 people have signed up the service and there have been over 48,000 enrolments onto dementia studies.
- The service is delivered in partnership by the NIHR and our charity partners: Alzheimer Scotland, Alzheimer's Research UK and the Alzheimer's Society





Join Dementia Research

Safe and secure

Ethically-approved studies only

Approved by Health Research Authority

Funded by Department of Health and Social Care



Join Dementia Research: Why is it needed?

There are currently 850,000 people living with dementia in the UK. This is set to rise to 1 million by 2025.

It is only through **research** that we can improve **diagnosis**, **treatment** and care and hopefully one day find a cure.

So if you are **looking for studies** to take part in, but don't know where to find them, please visit:



www.joindementiaresearch.nihr.ac.uk



Why people like taking part in research







Join Dementia Research: how it works

- Anyone with or without dementia can sign up
- People can register on behalf of someone else
- Variety of studies from prevention and treatments to improving quality of life
- Individuals choose which studies they take part in.
- Register online or over phone.



Our research participants say:

"There currently is no cure and without willing volunteers to try out new drugs there will continue to be no cure. Taking part in research is my way of feeling useful again and contributing to finding that elusive treatment which in turn will create a better world for my children."

"I love being involved in research. I am well looked after, I have interesting discussions, I gain an insight into the latest theories, and it keeps my brain active. I also have a better understanding of my disease progression than I would otherwise have. I find being involved in research is a therapy in itself as it helps me maintain a positive attitude to life."

Our researchers say:

"Research staff found Join Dementia Research easy to use and a great resource for the study. We are indebted to JDR for helping us achieve our recruitment target on time" - Study Coordinator "Join Dementia Research has been instrumental to the successful recruitment of patients in a current large commercial study. Half of our randomised patients and a third of our participants in screening have been recruited from JDR. By allowing patients to leave their details on the site, the system is putting the power back in patient's' hands to volunteer for studies" - Researcher

Join Dementia Research: How to sign up

Provide some **information about yourself** which will enable the service to match you to suitable studies.

- Online: <u>www.joindementiaresearch.nihr.ac.uk</u>
- Over the phone: call our helplines
 - Alzheimer Scotland (0808 808 3000)
 - Alzheimer's Research UK (0300 111 5 111)
 - Alzheimer's Society (0333 150 3456)
- By post: pick up a paper form and send back to us.



Facebook: /joindementiaresearch



Twitter: @beatdementia





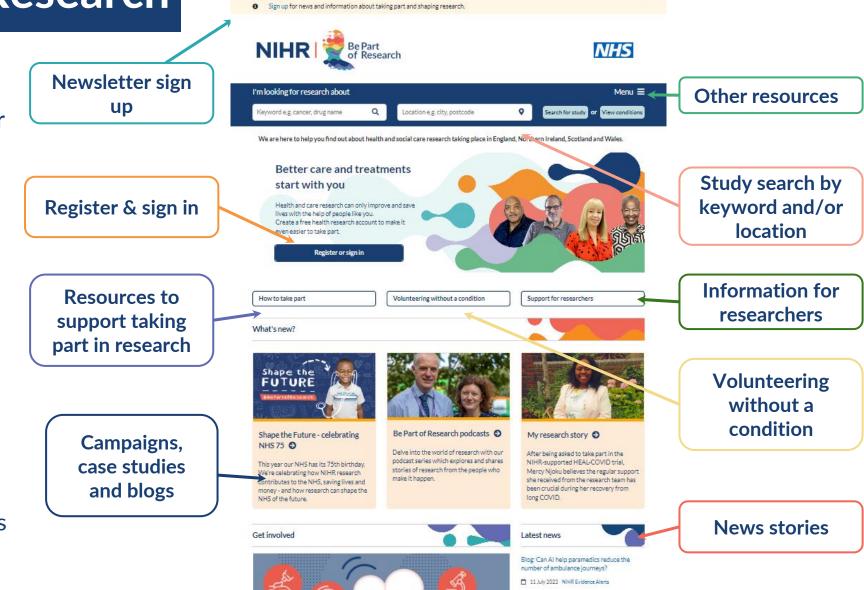
NIHR Be Part of Research

Engaging and informative helping the public to find and take part in health and care research, search for studies and sign-up for regular updates.

A service for everyone across the **general public and the research system**, informative, easy to navigate - providing a UK hub for research.

Resources for the public and links to connect the wider research community.

Volunteer registry connects studies with research-ready volunteers.



Keep up to date

