

What is research?

- Research is a process to gain new knowledge.
- Research aims to improve services and benefit patients.
- Research results are used to influence future NHS practice.

Why is research important?

- Research is important as it helps us to understand how best to look after people.
- Research can provide information to help decide where funding will be spent.
- NHS Trusts that are more active in research have been shown to have better outcomes compared with organisations that do less research.

What are Research Ethics?

- Health research is governed by the Care Act 2014.
- Ethical guidelines are followed.
- All research involving patients goes to independent NHS Research Ethical Review.
- The safety and well-being of the individual prevail over the interests of science and society.

Who is involved in research?

Anyone can be involved in research. This could be:

- Service Users
- Carers
- Relatives
- Staff
- The public

Under the NHS Constitution we are obliged to offer those who use our services the opportunity to take part in research which may be relevant to them.

If your clinical team thinks you may be eligible for a particular research project we may approach you to see whether you would be interested in taking part or finding out more information.

Who is doing the research?

A number of people are usually involved in running research projects. This could be:

- Clinicians from the NHS
- Academics from Universities
- NHS Clinicians/Investigators working with Commercial organisations
- Service Users and Carers

This research may also have received funding. This could be from:

- NHS England
- The National Institute for Health Research
- UK Research and Innovation and Research Councils
- Medical research charities
- Industry and commercial companies

Each project is different and will involve different people and partnerships. You will be told who the partners and funders are in research projects.

Do I have to take part in research?

- No. Only people who want to be involved will be included.
- Researchers will be careful to ask about consent and willingness.
- Part of checking that people want to be involved means giving a full explanation of what is involved in a way that is understood.
- Anyone who doesn't want to be involved can choose not to, or stop at any time.
- Some research may be done without consent which would only be done using anonymised data.

Can I join a research mailing list?

Yes. We have three mailing lists to keep in touch:

- The Dementias and Neurodegenerative Diseases Research Network, or 'DeNDRoN' Case Register is for people interested in research in the areas of dementia or neurodegenerative disease. This includes conditions such as Alzheimer's disease, Parkinson's disease and Huntington's disease.
- The 'Mental Health Research Register' is for people interested in research in the areas of mental health, developmental conditions, and addictions. This includes conditions such as Psychosis, Depression, Bipolar Disorder, Autism, Alcoholism and Drug Addictions.
- The 'Neurological Disorders Research Register' is for people interested in research in areas including Stroke, Traumatic Brain Injury, Dystonia, Cerebral Palsy and Spinal Injuries.

People who sign up are contacted about research studies they might be interested in. You will occasionally receive newsletters with information about public events and progress in research. Being on either of the registers does not mean you have to take part in anything. You can come off the mailing list if you don't find it useful.

What types of research do we do?

We do many types of research studies. These can include:

- Questionnaires and surveys
- Interviews and focus groups
- Psychological treatments
- Other interventions
- Medication or device trials

We also use a Clinical Records Interactive Search (CRIS) system. This allows anonymised data to be part of trust wide and national research.

How can I get involved?

If you would like some more information you can:

- Sign up to the Mental Health Research Register by emailing research.register@ncl.ac.uk
- Sign up to the DeNDRoN Case Register or the Neurological Disorders Research Register by emailing Dendron@cntw.nhs.uk
- To get more information about any of the research we do at CNTW, contact researchdelivery@cntw.nhs.uk or call 0191 246 7388 and leave a message.

What if I don't want to be involved?

Only people who want to be involved will be included. Researchers will be careful to ask about consent and willingness.

If you would prefer not to be notified about potential research projects, please speak to your clinician. There is also a national opt out here <https://www.nhs.uk/your-nhs-data-matters/>

Thank you for reading this information leaflet.

We are grateful to all participants who have helped develop this leaflet and the research projects in CNTW. Please get in touch if you have any further questions



Further information about the content, reference sources or production of this leaflet can be obtained from the Patient Information Centre. If you would like to tell us what you think about this leaflet please get in touch.

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