

www.dendron.org.uk

INFORMATION ABOUT POSSIBILITIES FOR PARTICIPATION IN RESEARCH STUDIES

This information sheet not a substitute for consulting a specialist doctor, but it may provide you with some useful information or be useful to have when seeing a specialist. Consultants and specialist nurses caring for a patient are best placed to know what research studies there might be in your area.

Participation in research studies means volunteering to take part in a piece of clinical research testing new treatments, new clinical methods or investigating disease processes. The DeNDRoN research studies which have so far been adopted onto the UK Clinical Research Network portfolio are described on the following website: <http://public.ukcrn.org.uk/search/>

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This information has been prepared in response to enquiries from individuals around the country who want to find out about research.

Research is important in helping to find the best possible treatments, improving quality of life, or finding the best possible new approach to care. New treatments or models of care tend to be compared alongside the best currently available.

Please note:

- There may not always be a current research study suitable for you (or a friend or relative) to take part in, which may be disheartening for people keen to explore possibilities.
- There is no easy way to work out what research studies might be suitable for a particular person.

It is always important to talk over any potential advantages and disadvantages of research with your doctor or nurse.

RESEARCH REGISTERS

So far, these registers tend to be written for health professionals. Some are very complicated and confusing. However, the information they contain might prompt some questions to raise when seeing a local specialist.

If you cannot use the internet, or find these too complicated, these websites still have information which your doctor or nurse might find of some help.

All research studies have guidelines about who can take part – ie ‘inclusion and exclusion criteria’ for who is and isn’t suitable. For example, studies may exclude people who are already taking a drug that may interact with the treatment being studied. Some trials only include people of a certain age, or at a particular stage in their illness. Many are restricted to specific types of people and sometimes only certain hospitals or parts of the UK are involved.

These are not complete lists of all the clinical studies currently recruiting participants in the UK. Some studies are no longer recruiting, but are still on the registers. Also some are only open to one or two local places.

United Kingdom Clinical Research Network and DeNDRoN

<http://public.ukcrn.org.uk/search/>

This mentions the DeNDRoN research studies which have so far been adopted onto the UK Clinical Research Network database.

The number and range of DeNDRoN research studies will steadily increase. Our studies can also be reached via links from the DeNDRoN website:- www.dendron.org.uk

It is the total collection of all the United Kingdom Clinical Research Network (UKCRN) studies. This means not just DeNDRoN, but also many different topics, e.g. Diabetes, Stroke, etc. This forms the “UKCRN Portfolio Database”. Although the Health Departments in Northern Ireland, Scotland and Wales are making local arrangements to meet their own requirements, all the UK Health Departments are working together to ensure that the new systems are integrated and aim to become more ‘patient-friendly’ over time.

MRC Clinical Trials Unit

www.ctu.mrc.ac.uk/TakePart.asp

This describes studies that the Medical Research Council’s Clinical Trials Unit runs.

However it doesn’t currently have much detail of dementias or neurodegenerative disease-specific studies. It is useful because it contains excellent, thought-provoking general advice about clinical research.

The National Research Register Archive

<https://portal.nihr.ac.uk/Pages/NRRArchive.aspx>

This is the old database of research studies relevant to the NHS, based on records collected up to September 2007. Many studies it mentions are now already completed, but some are ongoing research.

Since late 2007, information on research studies funded by the NHS, or relevant to the NHS, has started to be integrated into the United Kingdom Clinical Research Network's (UKCRN) Portfolio Database above.

Current Controlled Trials website

www.controlled-trials.com

This is very complicated, but useful for giving a picture of all the different research going on around the world. It does a very broad international search across lots of clinical research registers. It is published by a medical publishing company and the information is very much geared towards professionals and researchers rather than participants.

An explanatory note about the different PHASES of Clinical Research Studies

DeNDRoN's focus is on "Phase 2" and "Phase 3" clinical research studies, but is also concerned with trying to push forward the frontiers for new ideas for good quality clinical research of relevance to patients and carers.

PHASE 1 studies are very small early research; they only involve a tiny number of people who try out a new drug, or a new approach to improving quality of life, such as a type of medical equipment or a "model of care". Any new drug is tested on people only if extensive laboratory work shows promising results, and the participants are monitored extremely closely for side effects.

PHASE 2 studies follow, if Phase 1 results are good. These studies are larger, aiming to confirm whether a promising new drug or model of care actually helps, without causing unexpected events or adverse side effects. New treatments or models of care tend to be compared against the best currently available.

PHASE 3 studies are much larger still. They often involve thousands of patients over many years. This research looks at the effects of a drug or model of care over time, to assess just how beneficial the outcomes are. Phase 3 studies are also used to work out the best dose of a drug, or best method of using a new model of care. Patients are sometimes divided randomly into groups to detect small differences between the overall effects over time.

Patient Information and Patient Organisations

NHS Direct Online information for patients

www.library.nhs.uk/forpatients/

This doesn't provide information about specific trials, but gives general health information for patients, and a list of websites accredited by NHS Direct. It mentions some of the larger medical charities concerned with dementias and neurodegenerative diseases.

This site also has some good clear pages about how clinical trials work generally, and what to expect if you take part in a trial.

Alzheimer's Society www.alzheimers.org.uk

Parkinson's Disease Society www.parkinsons.org.uk

The Cure Parkinson's Trust www.cureparkinsons.org.uk

Motor Neurone Disease Association www.mndassociation.org

Huntington's Disease Association www.hda.org.uk

Lewy Body Association www.lewybody.org

Progressive Supranuclear Palsy Association www.pspeur.org

DeNDRoN www.dendron.org.uk

Patient and public involvement (PPI) allows patients or carers to have a say in the overall planning of dementias and neurodegenerative disease research – e.g. sitting on a committee in one of our local networks in England, or helping to decide research policies at a UK-wide level. This is different from being a participant in a research study.

INVOLVE www.invo.org.uk

INVOLVE aims to promote and support active public involvement in NHS, public health and social care research generally. It is not specifically connected to any particular disease.

People in Research website www.peopleinresearch.org

This is supported by the NHS. It lists organisations which want to actively involve members of the public in all aspects of planning research priorities to make clinical research more relevant to people's needs and concerns.