Personal Information collected:

- Your name and address
- Telephone number
- Email (if you use one)
- Whether you live alone
- Date of birth
- Gender
- Diagnosis
- Date of diagnosis
- GP’s name and address
- Hospital consultant’s name
- NHS number
- Hospital number
- Medication
- MMSE Score if appropriate
- Next of kin/carer name and address

Dementias and Neurodegenerative Diseases

Please telephone: 0191 223 2740

or write to us at:

DeNDRoN
St Nicholas Hospital
Jubilee Road, Gosforth
Newcastle upon Tyne
NE3 3XT

or email: dendron@ntw.nhs.uk

or contact us through the website

www.dendron.nihr.ac.uk/northeast

Case Register Information Leaflet for Patients and their Relatives or Friends

Version 9 August 2013
Joining the Case Register

We ask you to sign a consent form allowing us to hold information about you. The consent form can be signed when we visit you at home, or you can return it to us in the post. You do not have to join the Case Register and it will not affect the quality of your medical care at all if you decide not to.

Points to remember:
- You do not have to take part in any studies we tell you about.
- We will contact you from time to time to check that you still want to be on the Case Register.
- You are free to leave the Case Register at any time without giving a reason. Withdrawing from the Case Register does not change your medical care in any way at all.
- If you wish to talk about your or your relative’s participation in the Case Register, then please contact us.

What happens after signing the consent form

We send a copy of your consent form to your GP and hospital doctor, and return one to you.

We may contact you about new studies that might be suitable for you. These could involve different tests such as medical examinations, questionnaires, scans or blood samples. It is completely your choice to join in a study or not. There is unlikely to be a suitable study for all Case Register members.

We send out regular newsletters updating you about our research.

What happens to the information

The information on the Case Register is stored on a secure computer and is only used by authorised Clinical Research Network staff. Your contact information is passed to research teams only if you tell us that you wish to be involved in their research. Your information will be held by us for as long as a research network for dementias and neurodegenerative diseases exists. If the network should cease to exist, all information would be destroyed.