The staff at the National Amyloidosis Centre records information about you and your health so that you can receive the right care and treatment. We need to record this information, together with the details of the care you receive, because it may be needed if we see you again.

We may use some of this information for other reasons, for example, to help us to protect and improve the health of the general public, to plan for the future, to train staff and to carry out medical and other health research for the benefit of everyone. We are currently involved in a medical research study, within amyloidosis, which will use this information in a de-identified form.

Amyloidosis patients often go undiagnosed for a long period of time, with patients requiring multiple hospital visits before they are finally diagnosed. There still are large gaps of knowledge about amyloidosis, especially when looking at particular subtypes of amyloidosis.

Your de-identified information will support researchers in generating a better understanding about amyloidosis patients’ use of the NHS and support the development of ways to improve diagnosis and treatment of patients with amyloidosis. The results will also support in designing more efficient NHS services for amyloidosis patients potentially lessening the burden on patients by helping to reduce repeat visits during a patient’s diagnosis period as well as supporting earlier diagnosis for patients. In heritable forms of the disease the benefits may well subsequently help patient’s family members. The results generated could also provide evidence to support applications for novel therapies in this highly underserved disease area, potentially allowing patients in future to get access to new treatment options.

The risk of you being identified from the information provided is extremely low as all directly identifiable details (name, address, post code, telephone numbers, NHS number, full date of birth) are removed from your information before they are used for research, and all information will be checked for identifiable details by an automated process before researchers will look at it. Your information from the NAC will be anonymously linked with other NHS data for the purpose of this research. In order to do so your NHS number will be shared from the NAC to NHS digital, the national provider of information, data and IT systems for health and social care. This is the NHS entity who looks after your health and care information.

The research will be conducted by researchers from a company outside the NHS which does not and will not have access to your personal details, only to your de-identified information as outlined above. All researchers receive extensive training on data handling and security to ensure your de-identified information is managed with the greatest care.

If you would like to opt out of this research, please let your doctor know and no information from your records will be collected for use in this study. This will not affect your care in any way.

If anything to do with the research would be helped by you providing additional information about yourself, you will be contacted to see if you are willing to take part: You will not be identified in any published results.

A list of published research from this study can be found at http://www.imsheorbibliography.com/ or please contact Edmund Drage on telephone number 020 3075 5784 or email edrage@uk.imshealth.com for a paper copy.

Note that you have a right of access to your health records. If at any time you would like to know more, or have any concerns about how we use your information, you can speak to Julian Gillmore Telephone number: 020 7433 2816 or email j.gillmore@ucl.ac.uk.