



## CHARMER (CompreHensive geriAtRician led MEDication Review)

### Information you need to know:

This research project is being conducted by School of Allied Health Professions, part of the University of Leicester, assisted by the Norwich Clinical Trials Unit at the University of East Anglia.  
Further information on the institution can be found here: <https://le.ac.uk/>  
The University of Leicester is the Data Controller for your information.

The Data Protection Officer is: Parmjit Singh Gill, who can be contacted at: DPO, Legal and Information Assurance Services, University Of Leicester, University Road, Leicester, LE1 7RH.  
Email: [dpo@leicester.ac.uk](mailto:dpo@leicester.ac.uk)

This privacy notice explains how we use your personal information and your rights regarding that information.

### What information are we collecting?

Information is being collected from medical records held by the NHS, from questionnaires completed by patients and health care professionals, and from interviews.

Data, which may be collected with or without consent, from medical records will include:

- Your medical history
- Your hospital admissions history
- Your prescription history

If you are invited to consent to take part, and decide to participate, a researcher will ask you some questions about yourself, and will then ask you to fill in a questionnaire, followed by a telephone conversation to ask you the same questions again after 3 months to see if anything has changed.

You may also be asked if you would agree to an 'interview', this will be one of our researchers asking you some questions about your experiences during your hospital stay

Information we will collect from you, the questionnaires and interviews will consist of:

- Your name;
- Your age;
- Your contact details, such as your email address and telephone number;
- Your postal address.

We may also need to collect some information which is classed in law as 'special category data', this means that it is more sensitive and our researchers will treat this with extra care. You will be informed that we are collecting this, and asked if you are sure that you agree to it. This is information such as:

- information concerning your health;
- Your racial or ethnic origin;

### Why are we collecting your data?

We will collect your health data and, if you consent to take part, your personal data for our research and to contact you to arrange follow up telephone calls to ask you the questionnaires after 3 months. If you have indicated that you wish to be kept informed of the results of the study we will also use your contact details to provide you with an annual newsletter

Our study aims to evaluate whether an approach developed by researchers at the University of Leicester can help doctors and pharmacists to stop medications in hospital that may cause harm. We are interested to see if this approach improves older people's quality of life, as well as if it can reduce the number of times people get admitted to hospital.

### How we will use this data?



Any data collected for the study will remain strictly confidential and held securely on paper and electronically under the provisions of the 2018 Data Protection Act

Data will be held by either the University of Leicester or the University of East Anglia (UEA).

#### **How will data be used to link to NHS England held national datasets**

Personal information (NHS number, date of birth and full post code) are being collected on all patients admitted to the study ward, with and without consent, in order to link to NHS England held national datasets including:

- Your medical history
- Your hospital admissions history
- Your prescription history

Using data held in national data sets is the most efficient way of accessing the data needed to answer the research question, both in terms of the time taken and cost of undertaking the research. Public and patient involvement (PPI) representatives have reviewed what data is being accessed and how it is being accessed and have agreed to the approach used. The personal data collected for data linkage purposes (together with a unique study ID), is being sent securely from the participating hospitals to the Norfolk and Norwich University Hospital NHS Trust (NNUH), where it is being collated into a single dataset. This collated dataset will then be sent securely to NHS England to link to the national datasets. The data received by the research team at the University of East Anglia (UEA) will not contain the identifiable data. NHS England and NNUH will delete the identifiable data used for linking to the NHS England held datasets once confirmation of valid data has been issued by UEA. The research team have no access to the personal data used for data linkage.

#### **If I have given consent, how will my data be used**

- Any information containing your personal details, or which could identify you will be kept in locked storage or in our secure computer server.
- Any documents or recordings containing your information will be held according to the University information security policies
- Questionnaires and your consent forms and any other documents which contain your personal data will be held securely
- If you chose to complete the second questionnaire over the telephone, your answers will be transcribed by a member of the research team and will be entered directly into our computer system.
- If you have had an interview, audio recordings we have made will be transcribed (written down) word for word using a professional transcription service who are bound by a confidentiality agreement.
- Recordings will be deleted once we have transcribed them.
- Where you have given consent, only members of the research team from the University of Leicester and the University of East Anglia will have access to your identifiable data.
- Your contact details will be destroyed when we no longer need them for the study, this will usually be once we have used them for your final interview or telephone call, unless you have requested to receive results of the project.

### **What is the legal basis for processing the data?**

The University of Leicester legal basis upon which we will process your personal information for research activity is public task and this is set out in Article 6 of the GDPR *"Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller"*.

Please note the official authority to carry out research is expressed in the [University's Charter](#) in section 13 (b).

The CHARMER trial uses the electronic health care data of patients admitted to the study wards with, and where applicable, without obtaining informed consent. It is important for the trial to ensure that the results are reflective of the population to which the CHARMER intervention could benefit. Some patients admitted to the study wards may not be able to make decisions for themselves, and may not have a consultee – friend or relative – available to ask. Some patients may only be on the study ward for a short duration which does not allow time for researchers to discuss the trial with them. The CHARMER trial has been reviewed by Health Research Authority, Research Ethics Committee and



Confidential Advisory Group, and granted 'Section 251 Approval'. This means that data from electronic health records can be provided to the CHARMER research team in a way that it is not possible to identify individual patients. Checks are in place to ensure that data is not shared where an 'opt-out' has been requested for sharing of data for research purposes.

## If we are sharing your data with others who are we sharing it with?

We will share your personal data within University of Leicester, The University of East Anglia, The Norfolk and Norwich University Hospital NHS Foundation Trust and NHS Digital. Outside the NHS, this information will only be accessed by the research team.

Before it is shared anywhere else it will first be coded (pseudonymised) and only the research team in the organisations listed above will have the code to identify your data.

This means that although we share our research findings with other universities, research sponsors and auditors, your identity will be kept secret.

This is normal practice and usually happens before research data is shared or research outcomes published. If you would like to have further details about how your personal data is shared please contact the research team of the project.

The anonymised results of the study will be shared at medical conferences and in scientific journals so that your research participation also helps others going forwards.

## How long we will process your data for?

Your personal information, such as your name and contact details, will be processed and stored for a maximum of one year after the study has ended. Audio recordings will be deleted once we have transcribed them, prior to the end date of the study.

## What are your rights and how to enforce them?

As a research participant you have the following individual rights under Data Protection legislation:

- Right to be informed
- Right of access
- Right of rectification
- Right to restrict processing
- Right to object

However, please note that some of these rights may be restricted if the exercise of these may seriously impair research outcomes. It is also important to understand that these rights will only apply if the research project holds identifiable information about you. Where your information has been completely anonymised this information is no longer accessible and is therefore not classed as personal data for the purposes of the Data Protection Legislation. Therefore the rights specified above will no longer apply.

To find out more, or to ask for any of these rights, please contact the University Information Assurance Service: [ias@leicester.ac.uk](mailto:ias@leicester.ac.uk)

## How to complain to the Information Commissioner's Office?

The Information Commissioner can be contacted on:

Post: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK95AF.

Tel: 0303 123 1113.

Email contact can be made by accessing [www.ico.org.uk](http://www.ico.org.uk)