

**UNIVERSITY
of HULL****Centre for Addiction &
Mental Health Research**

Privacy notice: Screening, Assessment and Prevalence of Alcohol-Related Cognitive Impairment (ARCI) (SPARCI)

This privacy notice is for the above study.

The SPARCI study seeks to identify the prevalence of alcohol-related cognitive impairment (ARCI) in adults, with alcohol use disorder who have been admitted to hospital, using validated screening tools and cognitive assessments. Participants are followed up to understand longer term outcomes. The study will also help to evaluate the predictive value of cognitive screening tools used in hospital settings.

Full information on the study and what is involved for participants can be found in the Participant Information Sheet.

Who is involved in the delivery of the study?

The Hull Health Trials Unit (HHTU) at the University of Hull (UoH) are working in collaboration with a wider research team to deliver this study.

- The sponsor of the study is University of Hull
- The Data Controller is University of Hull
- Data Processors are University of Kent and University of York for statistical analysis

This document focuses on the UoH role as data controller for the study.

What personal data are we using?

This study requires the following information to meet the objectives of the study:

Participants who consent to the SPARCI study, the following personal data will be collected:

- Name
- Contact Details: Address (inc postcode), Phone numbers, email address
- GP Details
- NHS Number
- Birth data: MM/YYYY
- Demographical: Age, sex, gender, ethnicity, marital status, living situation and employment and education status
- Health data including current conditions and admission diagnoses (consent optional), service use and self-reported health behaviours and cognition data
- Name, relationship and contact details of persons who will act as locators in the event participants cannot be contacted (consent optional).

How will we look after participants data?

Pseudonymisation	Personal details that can be used to identify participants will be removed and all study documents will be assigned a unique Participant Identification Number. Only the local research team will be able to link this number to the participant. This is called pseudonymisation.
REDCap Cloud (RCC) and Box	The participants data will be managed and stored by HHTU using their data capture system REDCap Cloud (RCC) and BOX Governance file storage system. Both systems have high levels of security, and all data is stored within the EU. Only staff working on this study will have access to participants' data. Staff have individual logins and all activity is logged.
Paper management	Any source data collected on paper by UoH will be held within our secure storage space protected by ID card entry and within a key operated locker.

The HHTU has a Data Security and Protection Toolkit (DSP) (EE133824-HHTU) which provides assurance that we are practicing good data security and that personal data is handled correctly. More information about the DSP can be found here:

<https://www.dsptoolkit.nhs.uk/OrganisationSearch/EE133824-HHTU>.

Who has access to the data?

UoH staff working on this study will have full access to the data collected. In addition, regulatory organisations may require access as part of their oversight.

A statistician employed by University of Kent and a health economist employed by the University of York will receive pseudonymised data for analysis and will not be able to identify the participants.

The following additional sub-processors are in use for this research project for the purposes outlined:

- Cambridge Cognition provides the electronic cognitive assessment software (CANTAB) used in the SPARCI study. Participants complete these assessments on an iPad during research visits. To enable the assessment scoring process, participants' birth data (month and year), gender and education level are shared with Cambridge Cognition. Cambridge Cognition acts as a data processor for the SPARCI study under a contractual agreement. Data may be retained by Cambridge Cognition and used for other purposes. This data is anonymous to them and individuals cannot be identified.

How long will we keep the study data?

In line with study sponsor requirements, personal data will be retained in an archive for 10 years after the study has ended.

Data protection and legal responsibilities

The organisation that collects and processes the information described in this notice is the data controller. This means that it has the core legal responsibility to safeguard the information and

ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called “GDPR”) and a new UK law, the Data Protection Act 2018.

As data controller for SPARCI, the UoH must:

- Take steps to ensure that the data it processes is accurate and up to date;
- Give participants clear information about its processing of their data, in one or more privacy notices like this one and the participant information sheet (referred to together in this section as a “Privacy Notice”);
- Only process the data for specific purposes described in a Privacy Notice, and only share the data with third parties as provided for in a Privacy Notice; and
- Keep the data secure.

The law states that we can only process the participants personal data if the processing meets one of the conditions of processing in GDPR Article 6.

As we are processing special category data we also must meet one of the conditions in GDPR Article 9.

Special Category data includes personal data which relates to ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership.

Under the data protection legislation, we need to explain the legal basis for holding participants data, i.e. which of these conditions apply.

For our research project, the following conditions apply:

- Article 6.1 (e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that UoH performs in the public interest, as part of our core function as a university;
- Article 9.2 (j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes. This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests.

What are the participants rights?

Under the data protection laws, the participants have a number of rights in relation to the processing of their data. These are limited by the lawful basis under which we hold their data. The participants’ rights are:

- Right to request access to their data as processed by UoH and information about that processing
- Right to rectify any inaccuracies in their data
- Right to place restrictions on our processing of their data

If a participant would like to exercise any of their rights as outlined above, they can contact the DPO using the details given below.

If a participant has any questions or concerns about how their data will be processed within this project, they can contact HHTU in the first instance:

- Email: hhtuenquiries@hyms.ac.uk
- Telephone: 01482 463444

- Address: 3rd Floor, Allam Medical Building, University of Hull, Hull, HU6 7RX

If a participant would like further information, they can contact the University of Hull, Data Protection Officer (DPO):

- Email: dataprotection@hull.ac.uk
- Telephone: 01482 466594
- Address: University of Hull, Cottingham Road, Hull, HU6 7RX

We will always aim to respond clearly and fully to any concerns participants have about our processing and requests to exercise the rights set out above. However, if a participant has concerns about our data processing or consider that we have failed to comply with the data protection legislation, then they have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: <https://ico.org.uk/concerns/>

Email: casework@ico.org.uk

Tel: 0303 123 1113

Post: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF