

Informing an assessment pathway for alcohol-related cognitive impairment: A longitudinal study of screening, assessment and prevalence

Participant Information Sheet

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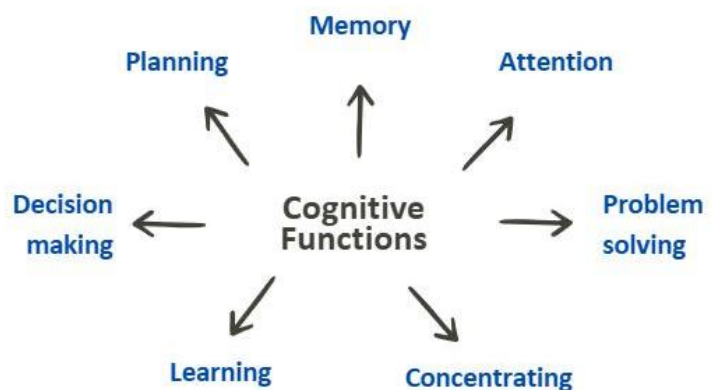
We would like to invite you to take part in a research study.

Before you decide, it is important that you know why this study is being done and what taking part would mean for you. Please read the information below and ask us if anything is unclear.

- Taking part is completely voluntary.
- Your decision will not affect your care or treatment in any way.

What is this study about?

Alcohol use over time can affect how the brain works. It impacts how you remember things, pay attention, plan and make decisions, solve problems and learn new information (**cognitive functions**). A broad term for these kinds of difficulties is **Alcohol-Related Cognitive Impairment (ARCI)**.



- ARCI can range from:
 - Mild and temporary problems
 - Severe and long-lasting problems
- Recovery is possible and stopping drinking completely (abstinence) often helps improve cognitive functions or stops them from getting worse over time.
- Difficulties with remembering and paying attention can also happen for other reasons, such as:
 - being unwell in hospital
 - taking certain medications
 - alcohol withdrawal
- Because cognitive difficulties can be short or long lasting and can happen for other reasons, it is important to check these difficulties regularly. We will do this using a cognitive assessment.

Cognitive Assessment

- This is a set of questions and tasks that look at different cognitive skills, such as memory, attention, problem-solving, and planning.
- It is important to know that the assessment is not a test of intelligence.
- It is not about getting the answers right or wrong, but about understanding your current abilities.
- We will ask you to complete a short cognitive assessment on paper in hospital and a longer assessment on a touch screen computer 4 to 8 weeks later and again, 6 months later.

In this study,

- We want to understand how common cognitive difficulties in patients with alcohol problems are.
- We also want to see how these cognitive difficulties change over time.
- This study will help us find out if a short cognitive assessment works well in hospital and whether it can track changes over time.
- We also want to understand how medication, alcohol use, and other health conditions may alter cognitive difficulties and the use of health and social care services

What we learn will help improve how hospitals and community services identify and support people with alcohol-related cognitive impairment.

What will I have to do if I take part?

SPARCI

Screening

In hospital

Brief questionnaire about your alcohol use to check if you can take part in the study.

Time: Approximately 10 mins

Time 1:

In hospital

Information about yourself, including your age, sex, gender, ethnicity, education, work (current work and veteran status), relationship status, living situation, and postcode (to help us understand the area you live in).

Questionnaires about thinking/memory (cognitive function), alcohol use, physical and mental health and service use.

Time: Approximately 1 hour

Compensation: £15 voucher

Time 2:

4 - 8 weeks later

In hospital / community

Questionnaires about yourself, thinking/memory (cognitive functions), alcohol use, physical and mental health, and a breathalyser test.

Time: Approximately 2 hours

Compensation: £25 voucher

Time 3:

6 months later

In hospital / community

Questionnaires about yourself, thinking/memory (cognitive functions), alcohol use, physical and mental health, service use and a breathalyser test.

Time: Approximately 2 hours

Compensation: £25 voucher

Mandatory Information:

- We will ask for your GP details. This is in case we have any concerns about your health or wellbeing when we see you at follow-up if you are no longer in hospital.

Optional Information:

At the first appointment we will ask:

- If you are willing to let us access your medical records to see details of your current admission and how often you have been in the hospital during the 6 months before and after now.
- If you are willing for us to use your NHS number to collect up-to-date information about your health in the future by linking your data from different health and care services to the information we collect about you in this study. This could help us know where to target care better. We would seek approval from an ethics committee for any future study using linked data. Your data would be kept securely following strict data privacy laws. You will not need to do anything for this; we will collect this information from your health records and from other health databases.
- If you are willing to provide the contact details of a family member and/or friend and/or key health care professionals involved in your care, in case we have trouble reaching you for the follow-up.

What are the good things about taking part?

- You might not directly benefit from taking part.
- But, your participation will help researchers and healthcare professionals to:
 - Assess individuals in hospitals at risk of ARCI.
 - Track cognitive difficulties over 6 months.
 - Learn how to improve care for people with these difficulties.

What are the not so good things about taking part?

- Talking about drinking, cognition and your feelings might be upsetting. You can skip questions or stop anytime.
- Answering questions might be tiring. You can take breaks or come back later.

Why am I being asked to take part?

- You're in hospital right now, and your nurse or doctor thinks you might be able to help with this research.

Will I get paid for taking part?

- If you are eligible to take part in the study, you will receive a £15 voucher to thank you for giving up your time on the first visit in hospital. The second and third visits take up more of your time and therefore you will receive a £25 voucher for each follow-up visit. We are unable to reimburse local travel costs to get to the follow-up visits but if you need additional support to get around, just let us know.

What if I don't want to take part or change my mind?

- It's okay to say no, or to change your mind later. If you change your mind after you have consented to take part, you can withdraw from the study. You do not have to tell us why. This won't affect your care at all.
- If you withdraw from the study, we will keep and continue to use all your previously collected data. We would like to continue collecting information about your health from your hospital (if you have consented to this). If you do not want this to happen, tell us and we will stop. We will not contact you again.
- If you become too unwell to continue in the study, we will keep all information you have provided up to that point unless you tell us otherwise.

Will my information be kept private?

- Yes. All your information will be kept safe and private.
- We will share some test results with your hospital nurse or doctor in case it helps you get the right care.
- Confidentiality will only be breached if you or someone else is at immediate risk of harm .

What will happen to the results of the study?

- The results will be used to help hospitals and other health and care services give better care to people with alcohol problems.
- The results will be shared with other researchers and the public, but no one will know it was you.
- The results will also be available on our website: <https://www.hull.ac.uk/research/centres/centre-for-addiction-and-mental-health-research>

Who is organising and funding the study?

- The University of Hull is responsible for the research. The research is funded by the National Institute for Health and Care Research.

What if something goes wrong?

- If you have worries, talk to the research team.
- If you're still not happy, you can make a formal complaint.
- In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Hull or <enter site NHS Trust>, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Bradford Leeds Research Ethics Committee

Where can I get more information?

There are contact details below if you want to know more or want to take part.

For further information or to take part, please contact the researcher on the telephone: **xxxxxx xxxxxx**

If you are unhappy with any aspect of the study or would like more information and the hospital researcher is unable to help, please contact:

- Dr Philippa Case (leading the research): CAMHR_ARCI@hull.ac.uk or 01482 463297

If you are unhappy and the researchers above are unable to help, please contact:

- The University of Hull (responsible for this research): coo@hull.ac.uk
- Patient Advice and Liaison Service: hyp-tr.pals.mailbox@nhs.net, tel: 01482 623065

There are places you can get support if you need it – these are listed at the end of this leaflet.

What about my data?

- This section explains how your personal information will be used and kept safe during the study.
- It also tells you what choices you have about your information.

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act (2018). All research using patient data must follow UK laws and rules.

How will we use information about you?

We will need to use information from you and your medical records (where you have given consent) for this research project.

This information will include your:

- Name
- Contact details: Address (including postcode), phone number, email address
- Month and year of birth
- NHS number (where you have given consent)
- GP details
- Demographic information: Age, sex, gender, ethnicity, marital status, living situation and employment and education status
- Health data including current conditions and admission diagnoses (where you have given consent), 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 that you cannot be contacted (where you have given consent)

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

The University of Hull is the sponsor of this research. The University of Hull is responsible for looking after your information.

We will share your information related to this research project with the following types of organisations:

- Cambridge Cognition Ltd (CANTAB cognitive assessments) University of Kent (statistical analysis)
- REDCap Cloud (data collection)
- Box (secure data storage)

We will keep all information about you safe and secure by:

- using secure web-based systems called CANTAB, REDCap Cloud and Box to collect and store data for this study. These are all University of Hull approved suppliers that have been through a data protection impact assessment
- only entering an ID number and no identifiable information into the CANTAB system. CANTAB is owned by Cambridge Cognition Ltd and data may be retained by Cambridge Cognition Ltd for other purposes after the study, but this data is anonymised and no one will be able to identify you
- minimising the data that we enter into these systems (e.g. only using your month and year of birth instead of your full date of birth)
- only allowing access to this system to people who need it
- tracking access to the system to ensure it is not accessed by anyone who doesn't need access
- writing our reports in a way that no one can work out that you took part in the study

International transfers

We may share or provide access to data about you outside the UK for research related purposes to:

- store your anonymised data.

If this happens, we will only share the data that is needed. We will also make sure you can't be identified from the data that is shared where possible. This may not be possible under certain circumstances – for instance, if you have a rare illness, it may still be possible to identify you. If your data is shared outside the UK, it will be with the following sorts of organisations:

- Cambridge Cognition Ltd

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law. We will make sure your data is safe outside the UK by doing the following:

- the countries your data will be shared with have an adequacy decision in place. This means that we know their laws offer a similar level of protection to data protection laws in the UK
- we do not allow those who access your data outside the UK to use it for anything other than what our written contract with them says
- we need other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing
- we have procedures in place to deal with any suspected personal data breach. We will tell you and applicable regulators when there has been a breach of your personal data when this is legally required. For further details about UK breach reporting rules visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/report-a-breach>

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. We will keep your study data for a maximum of 10 years. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- If you choose to stop taking part in the study, we would like to continue collecting information about your health from your hospital. If you do not want this to happen, tell us and we will stop.
- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

- You can find out more about how we use your information, including the specific mechanism used by us when transferring your personal data out of the UK: at www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by contacting the University's data protection officer at data.protection@hull.ac.uk
- by ringing us on 01482 463297

Where can I get help and support?

- This section gives you contact information for places that can help if you're worried about drinking or your mental health.

HELP FOR ALCOHOL PROBLEMS

Local services:

Hull Community Addiction Services (RENEW): Offer free and confidential support for anyone affected by alcohol or drugs. Contact online:

<https://www.changegrowlive.org/hull-renew>. Phone number: 01482 62001



The OSHI Project: A peer-led service providing one to one support. Add: C4Di at The Dock 31-38 Queen St, Hull HU1 1UU. Tel: 07507 988 481, email: help@oshi.org.uk, contact online: <https://www.oshi.org.uk/about-oshi/>

Alcoholics Anonymous helpline (Hull): 01482 830083

National services:

Drinkline: A free, confidential helpline for people who are concerned about their drinking, or someone else's. Call 0300 123 1110 (weekdays 9am–8pm, weekends 11am–4pm)

Alcoholics Anonymous: Their helpline is open 24/7 on 0800 9177 650. If you would prefer, you can also email them at help@aamail.org or live chat via their website at www.alcoholics-anonymous.org.uk.

SMART: You can join a SMART Recovery meeting online here: www.smartrecovery.org.uk

SMART holds both face-to-face and online meetings which support people in managing problematic addictive behaviour. The SMART Recovery Programme has women's only meetings and those specifically for members of the LGBTQ+ community.

Support for families and carers

Adfam: Adfam is the national charity working to improve life for families affected by drugs and alcohol. It aims to empower family members and carers, support frontline workers and influence decision-makers to prevent alcohol and drugs from harming families. Using compassion and evidence, the charity informs, supports and empowers both people affected by a loved one's substance use and the workers who support them. www.adfam.org.uk Tel: 020 3817 9410

Al-Anon: Al-Anon Family Groups provide support to anyone whose life is, or has been, affected by someone else's drinking, regardless of whether that person is still drinking or not. The organisation is a fellowship of relatives and friends of alcoholics who share their experiences to solve their common problems. It has over 800 support groups in the UK and Republic of Ireland. www.al-anonuk.org.uk Tel: 0800 0086 811

Carers UK: Provides advice, information and support for carers. They also have an online community of carers and are available to Carers UK members 24 hours a day, 365 days a year. www.carersuk.org Tel: 0808 808 7777 (Mondays to Tuesdays, 10am-4pm)

HELP FOR MEMORY PROBLEMS

If you have any concerns about your memory, please speak with your GP

Age UK:

Age UK provide information, advice and a range of other services. Age UK Hull can be contacted Monday to Friday 8am to 4pm on: 01482 324644 or hello@ageukhull.org.uk

ARBD Network:

The ARBD Network has information and resources about alcohol-related memory and thinking problems: www.Arbd.net

Alzheimer's Society:

The Alzheimer's Society offer support for people concerned about dementia: www.alzheimers.org.uk

HELP FOR MENTAL HEALTH

Local services:

Let's Talk: Provide IAPT services for people with a Hull GP. IAPT stands for Improving Access to Psychological Therapies. Let's Talk can help you with common mental health issues. Complete an online self-referral form: <https://www.letstalkhull.co.uk/pages/make-a-referral>

The Emotional Wellbeing Service: Is an NHS organisation that offers talking therapy to people living in the East Riding of Yorkshire for a variety of mild to moderate mental health disorders. Self-refer to this service if you do not have a severe and enduring mental health condition but may have problems around past trauma, depression, anxiety, phobias, anger management and bereavement. Self-referral tel. number: 01482 335451 or text number 60163.

Crisis number: 0800 138 0990

MIND: Tel:(01482) 242808

QWELL: Effective and personalised digital mental health care. Commissioned by the NHS QWELL works in partnership with traditional NHS services: <https://www.qwell.io/>

National services:

Samaritans: To talk about anything that is upsetting you, you can contact Samaritans 24 hours a day, 365 days a year. You can call 116 123 (free from any phone), email jo@samaritans.org or visit some branches in person: <https://www.samaritans.org/branches/>

Mind: Provide information, support, local support services <https://www.mind.org.uk/about-us/localminds/>, they have an information line; 0300 123 3393 (9am-6pm Monday to Friday)