Participant Information Sheet

**Developing an online educational resource on alcohol and drug information for autistic adults: Evaluation Phase**

**Qualitative Interview**

My name is Gwyn Roberts and I am conducting this researchas a student in the Psychology PhD programme at Manchester Metropolitan University, Manchester, United Kingdom.

# What is the study about?

The aim of this study is to evaluate an educational resource on alcohol and drug information developed specifically for autistic adults. The initial development of the resource was guided by a previous study into the preferences and opinions of autistic adults on alcohol and drug education and resources.

Your responses are important in helping to evaluate the appropriateness and successfulness of the educational resource. Your answers will help to improve the resource, including what aspects need to be added or improved upon.

# Why have I been approached?

You have been approached because you are either an alcohol and drug health professional, an autistic adult with personal experiences of alcohol or drugs, or part of the “Autistica” Insight Group.

These groups have been chosen as they can all provide valuable insight on the educational resource, which has been specifically designed for autistic adults on the topic of alcohol and drug information.

# Do I have to take part?

No. It’s completely up to you to decide whether or not you take part. If you decide to take part and then change your mind you have the right to do so within two weeks from the day of the interview, without providing any reasons and without your rights being affected in any way. All research data collected until this point will be destroyed.

# What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to take part in an interview. There are a variety of different methods for the interview to be conducted, depending on your preference. You can either have the interview take place face to face or electronically (through video call, phone/audio call, or by email). It is important to note that both face to face and video or phone call will require you to arrange a time with the researcher, whereas the email interview can be completed in your own time.

**If you choose to meet face to face or via video or phone call:**

The researcher will be based at Manchester Metropolitan University and as such meeting will take place either on University property or the researcher can meet you at your charity or organisation. You will need to arrange via email when you would like to meet for the interview. When you arrive, you will meet the researcher and be presented with a consent form. Once signed, the interview will take place and will last approximately 30-60 minutes to complete.

If you wish to conduct the interview through a video or phone call you would contact the researcher through email and decide on a time and which application or option you would prefer. The researcher will email you a consent form that must be signed and returned before the interview can take place. The interview will then take place at the agreed time and will last approximately 30-60 minutes.

**If you choose to be contacted through email:**

First, you would contact the researcher via email and state your preference. The subsequent email you receive will contain the consent form that you will need to sign and email back. Afterwards, you will receive an email with the proposed interview questions for you to consider and answer. Once this is completed and emailed back, you will receive another email with questions that will relate to your answers in the previous email. Once they have been answered, you will receive a final email thanking you for your participation.

# Will my data be Identifiable?

The information you provide is confidential and will be made anonymous. Any personal data given will be kept confidential as all participants will have their details replaced with pseudonyms. No personal data will be discussed or used within the final report of the study. Additionally, data will be encrypted on a password protected device accessible only to the researcher. Direct quotes from participants will be used in the report of the study, however, only the participant and the researcher will be able to identify their own quotes as the report will not include the name or details of the participant. The research data collected for this study will be stored securely and only the researchers conducting this study and auditors will have access to these data:

* If the interview was conducted face-to-face then audio recordings will be destroyed and/or deleted at the end of the of data analysis. The interview will be converted into a typed version (not necessary to convert if interview was conducted through instant messenger or by email), which will be stored for 10 years after data collection.
* The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected and will be destroyed 10 years after data collection.
* At the end of the study, hard copies of consent forms (which contain personal sensitive data) will be scanned. The electronic files will be saved on a computer for 10 years. At the end of this period, they will be destroyed.
* The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
* All your personal sensitive data will be confidential and will be kept separately from your interview responses (i.e. research data).

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

If you change your mind about taking part, you can ask for your data to be withdrawn from the study. This means that any information you have provided will be securely deleted and therefore will not be used in the study. To withdraw your data simply contact the leader researcher (email provided on this sheet) and state that you wish to withdraw your data. This is because the data is anonymous and without the unique participant code, the researcher will not be able to identify your responses. Please keep a note of the unique participant code should you wish to withdraw your data. **You have until the 30/09/2022 to ask for your data to be withdrawn.**

**Data Protection and Transparency**

Manchester Metropolitan University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Manchester Metropolitan University will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained (but will destroy the research data). To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting ethics@mmu.ac.uk.

As a university we use personally-identifiable information to conduct research and our legal basis for processing personal data is a ‘public task’. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research.  This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the British Psychological Society (2018) Code of Ethics and Conduct and the British Psychological Society (2014) Code of Human Research Ethics.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Our Data Protection Officer is Christopher Woolley (contact C.Woolley@mmu.ac.uk or legal@mmu.ac.uk).

# What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal relating to autistic research.

# Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

# Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

# Who has reviewed the project?

This study has been reviewed and approved by the Faculty Ethics Committee at Manchester Metropolitan University.

# Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Lead Researcher

Gwyn Roberts

Email: 13161129@stu.mmu.ac.uk

Department of Psychology │Manchester Metropolitan University │Manchester │M15 6GX

Director of Studies

Dr Jennifer McGahan

Tel: (0161) 247 2403 │Email: jennifer.mcgahan@mmu.ac.uk

Department of Psychology │Manchester Metropolitan University │Manchester │M15 6GX

First Supervisor:

Dr Joanne Ashby

Tel: +44 (0)161 247 2594 │Email: j.ashby@mmu.ac.uk

Department of Psychology │Manchester Metropolitan University │Manchester │M15 6GX

# Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Jennifer McGahan

Director of Studies and Lecturer at Manchester Metropolitan

Tel: +44 (0)161 247 2403 │Email: jennifer.mcgahan@mmu.ac.uk

Department of Psychology │Manchester Metropolitan University │Manchester │M15 6GX

If you wish to speak to someone outside of the Department of Psychology, you may also contact:

Dr Claire Fox

Head of Research Ethics and Governance

Email: claire.fox@mmu.ac.uk

Educational Psychology, Faculty of Education│Manchester Metropolitan University │Manchester │M15 6GX

Thank you for taking the time to read this information sheet.

**Resources in the event of distress**

Should you feel distressed either as a direct result of taking part the following resources may be of assistance.

National Autistic Society helpline:

10am-4pm from Monday-Thursday, 9am-3pm on Fridays

0808 800 4104

National Autistic Society site:

<https://www.autism.org.uk/get-involved/about-us/contact-us.aspx>

Help with drug/alcohol addiction:

<https://www.nhs.uk/live-well/healthy-body/drug-addiction-getting-help/>