

Participant Information Sheet (PIS) – Field Trip Participants

Research Project title

Enhancing Accessibility for Autistic Individuals in Museum Digital Culture Experiences

Invitation paragraph

You are being invited to take part in a research project. Before you decide whether to take part, it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully.

The data collected as part of this study may be used, in part or in whole, for the writing of a PhD, at no time would any personally identifiable data be published without consent.

What is the purpose of the research project?

In museum programming and research, there is a major lack of projects centring on the experience and enjoyment of autistic adults in museums and cultural settings. Programming in museums has a child-focused bias and even when autistic children are the audience, learning retention is prioritised over enjoyment. This project aims to understand the experience and feelings of autistic adults when interacting with digital experiences in both museum and digital culture extended reality environments. A project goal is to understand what features of digital culture experiences create a negative or positive experience for autistic adults so that a baseline design format can be established and disseminated to the culture and museum sector. This research initiative aims to contribute to a wider inclusivity of autistic people in both autism research and digital culture experiences in museum spaces.

This research project aspires to be a progressive example of ethical, socially informed and disability rights-centred research, therefore, the field trip design and feedback-gathering methods will be designed in partnership with members of the autistic community during a pilot stage. Data will be gathered through a series of one-hour 'field trips' to the Jewry Wall Museum in Leicester and through 30-minute VR experiences conducted at the Innovation Hub in Leicester city centre. The primary researcher will accompany participants to conduct participant observation, make audio recordings, and prompt the participants to share their thoughts throughout the experiences. Follow-up questionnaires, interviews, and creative feedback methods will be used to gather further data.

The pilot, fieldwork, and participant feedback stages of this project will span from November 2024 to August 2025. Subsequent data analysis and document development will commence in September 2025 and extend until the beginning of the writing-up stage in January 2026. The project will conclude with the culmination of my doctoral thesis submission in December 2026-February 2027.

Why have I been invited to participate?

You have been invited to participate because this project aims to understand the experience and feelings of autistic adult individuals when interacting with digital culture experiences and you identify yourself to any degree as being autistic, having autism, or 'being on the spectrum'. Between 30-60 people will be asked to participate. Your participation is valuable and needed to shine a light on this area of the autistic experience in museums and digital culture. Your voice is integral to this research and has the potential to contribute to positive change in the design of museum and culture programming.

Do I have to take part?

It is up to you to decide whether or not to take part in this research project. If you do decide to take part you will be given this information sheet along with a privacy notice that will explain how your data will be collected and used, and be asked to provide your consent to participate. If you decide to take part you are still free to withdraw at any time and without giving a reason, by contacting the researcher. If you do withdraw, you will still receive the 'thank-you' payment.

What will happen to me if I take part?

Part of the study will take place at the Jewry Wall Museum in Leicester City Centre. Upon acceptance to participate through booking a timeslot for a field trip online, participants will be sent a welcome email explaining in more detail what to expect, links to the museum's website with accessibility information, and the required Participant Information Sheet (PIS) and consent forms. You will also be sent a 'Visual Story' for the field trip location with pictures and descriptions of the site and our planned route throughout it. In the welcome email, you will be provided a link to book a phone or video call with me ahead of time if you wish to ask questions or get to know me more before the field trip. You will also be asked to inform me of any accommodation needs ahead of your visit.

Participants will be met outside the main entrance of the Jewry Wall Museum. Admission will be free. We will walk together to a quiet location to sit and discuss what to expect and sign any required forms. We will also discuss safety procedures, what to do in a situation of discomfort or overstimulation, where quiet locations are, and your power to end the trip at any time.

The participant and researcher will walk through the museum, approaching each interactive installation, and you will be encouraged to interact with the installations as you want and to speak your thoughts aloud as you do. The researcher will have a discreet voice recorder operating throughout the field trip and will take notes on an iPad with the participant's permission. The researcher's role will be to casually engage with the participant through open-ended probing questions that arise in the moment such as, 'What do you like about this?' or 'What don't you like?'.

The field trip will last for no more than 1 hour. If the participant wishes to discuss the experience after the field trip, there will be a buffer of 15 minutes after each session. You will not be asked feedback questions upon completion of the field trip but will be encouraged to reflect on the experience over the following days. You will be emailed the feedback questions immediately after the field trip to guide your reflection during this time. Also in this email, you will be asked to respond in your chosen way within a week of the field trip and given a link to schedule this

response. You can choose either a follow-up phone call, video call, or provide written responses to the questions. You will also be given the option to provide your demographics at this time. Upon completion of the feedback, or upon your choice to withdraw, you will be transferred a £30 'thank you' payment for your time and expertise. The 'thank-you' payment is unconditional. You will receive it whether or not you complete the entire participant process. Afterwards, you can then choose to stay involved with project updates via a mailing list.

What are the possible disadvantages and risks of taking part? (where appropriate)

Participants are required to independently commute to the Jewry Wall Museum for their involvement in the study. Although minimal physical risk is associated with the act of occupying the designated space, museum staff will be made aware of our presence in the building and will be present to ensure the safety of the participants. Should participants have any apprehensions or anxieties related to visiting the museum, it is imperative to communicate such concerns to the researcher in advance of the scheduled field trip.

There is potential for the Audio Visual (AV) installations with their bright lights, loud sounds, and virtual motion to cause sensory discomfort and overstimulation. If you are aware of having sensory sensitivities to such external stimuli, please communicate this with the researcher and inform them of what you might need in the event of overstimulation. In the event of such a situation, the researcher has educated themselves on how to handle this by following guidance from both the Autism Research Institute and the National Autistic Society covering calming techniques in autism (ARI, 2024; NAS, 2020). The researcher will create a quiet, safe space, and give you time and reassurance should this occur.

What are the possible benefits of taking part?

Participating in this research study could benefit other autistic and neurodivergent people by providing valuable insights into how autistic adults feel about and respond to current digital cultural experiences. These insights could lead to significant changes in autism research and the design of digital culture experiences in museums, making them more inclusive and enjoyable for everyone.

What data will you collect about me?

The data I will collect includes:

- Observational (Behavioural, written notes on iPad)
- Audio (Microphone recording of field trip)
- Feedback Response (e-questionnaire, audio/video/written/creative responses)
- Optional Demographic data (e-questionnaire)

During the data collection, the objective is to collect accurate, autistic feelings and responses towards current digital culture experiences. The observational and audio data will be collected in person during the field trip. Feedback questionnaires will be sent out immediately after a field trip. Responses to the questionnaire will be collected within a week after the field trip once the participant has had time to digest the experience and think their responses through.

Will what I say in this research project be kept confidential?

All information collected during the research will be kept strictly confidential. You will not be identifiable in any reports or publications. An audio recording will be taken of the field trip and this will only be used for analysis. Your feedback responses, in any form they may be, will also be anonymised.

This study will at all times be covered by GDPR (2018) data protection regulations, which means that your name will be de-identified, given a code, and stored securely and safely on a password-protected University drive. If you wish at any time to withdraw your details, then this can be done via your unique identifier, which the researcher will manage in confidence.

How will you look after the data you collect about me?

We need to ensure that you understand what will happen to data we collect about you as well as your legal rights. This document is accompanied with a separate Privacy Notice providing further details, which I have attached to this email.

Your normal rights under the Data Protection Act and the General Data Protection Regulation apply. However, we need to manage your records in specific ways for the research project to be reliable. This means that we won't always be able to let you see or change the data we hold about you. The data gathered from you will be stored and protected on secure systems at all times.

You can stop being part of the research project at any time, without giving a reason, but we will keep information about you that we already have and continue to use this for the purposes of the research project as outlined here.

At all times this research study will comply with the General Data Protection Regulations (GDPR, 2018) approved by the EU parliament on 14 April 2016 and passing into UK law with effect from 25 May 2018. Any identifiable data will be deleted 6 years after the completion of my doctoral studies.

What will happen to the results of the research project?

The results will be published as a conference or journal paper as well as used as part of my PhD thesis. It is possible that the results could also be used for future research and consultation in this area. Additionally, the outputs of this project may be disseminated to the participating organisations to use in their efforts to improve their digital design accessibility. A copy of the findings, once completed, will be available to you if you would like it.

What should I do if I want to take part?

After booking a field trip time slot and/or an introductory video call through a provided link, you will be sent an email with all of the required documents. You will be asked to complete an Informed Consent Form and to opt-in to a variety of research options by ticking the Yes or No box. This will confirm you understand how your data will be processed, protected, and reviewed for research purposes. Those who wish to participate can contact the primary researcher, Shelby Navone at snn9@leicester.ac.uk. Trips to the museum will take place throughout August 2025.

Who is organising and funding the research project?

I am conducting the research project as a post-graduate research student at the University of Leicester in the School of Museum Studies and a fellow of the Institute for Digital Culture. This project is funded by the University of Leicester's Future50 studentship program. Funds for participation payments were secured through winning the Steven Simmons Bursary, which is distributed by the School of Museum Studies at the University of Leicester.

What if something goes wrong?

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it.

Who has reviewed the research project?

The research project has been approved by the University of Leicester Research Ethics Committee.

Contact for Further Information

Shelby Navone (PhD Student): snn9@leicester.ac.uk

Prof. Ross Parry (Supervisor): ross.parry@leicester.ac.uk

If you have any concerns or queries about how the research project has been conducted, you can contact the Chair of the University Research Ethics Committee on Ethics Chair: ethics@le.ac.uk

Contact information for a neutral contact at the University in the event of any queries or concerns:
Dr. Sarah Plumb: sp627@leicester.ac.uk

If you require more GDPR data protection information, then you can access this via the University's Information Assurance Services:

Information Assurance Services

University of Leicester

University Road

Leicester

LE1 7RH

T: +44 (0)116 229 7945

E: ias@le.ac.uk

W: <https://www2.le.ac.uk/offices/ias/>

Thank you for taking time to read the participant information sheet and looking forward to working with you!