

## **Participant Information Sheet: Asynchronous forum focus group**

### **SAAIL: Supporting Autistic Adults' Intimate Lives**

#### **1. Invitation to research**

Thank you for your interest in our study about autistic adults' intimate lives. This study is funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). You are invited to participate in an online text-based forum focus group discussion with other autistic adults. The forum discussion will be about autism and intimacy and your views on how to improve social support and resources for autistic adults in England to enjoy fulfilling intimate lives.

The researchers who will be conducting the focus groups are Monique Huysamen and Marianthi Kourti. We work in the Department of Social Care and Social Work at Manchester Metropolitan University.

#### **2. Why have I been invited to take part in the study?**

You are eligible to take part in the study because you identify as an autistic adult (self-identified or professionally diagnosed) without significant co-occurring learning disabilities, and you live in England.

#### **3. Do I have to take part?**

No. Once you have read all the information describing the study in this sheet and have asked any questions, you can decide if you would like to take part. We will send you a consent form and then ask you to sign the form and email it back to us. You will be free to stop taking part in the focus group at any time, without giving a reason.

#### **4. What will I be asked to do?**

If you decide to take part, you will join an online text-based forum discussion with 7-12 autistic people. We have already done interviews with 25 autistic people around their experiences with intimacy. In this focus group we will share some of the common experiences autistic people spoke about in these interviews and ask you to share your thoughts on these findings. We will ask you about your opinions about the kind of support and resources around intimacy that you think autistic people in England might benefit from.

The online forum focus groups take place on the discourse platform <https://www.discourse.org/>. The forum is asynchronous, meaning participants can log in and will discuss and interact on the forum in their own time and at their own pace over a number of weeks. You will be given log in details and detailed instructions about how the platform works and how the focus group will be structured. You will log in anonymously

using a nickname. The researcher will post one question/discussion point on the topic at a time and ask the group to discuss amongst themselves on the forum. The moderator will post a new question when discussion around the previous question is concluded. The forum discussion will remain open until all questions have been asked and the discussions have been concluded, with a maximum period of 1 month. You can choose when and how often you interact and contribute on the forum.

## **5. Anonymity and confidentiality**

Unless you specifically choose to participate in a focus group with a group of people you know, you will take part in the forum focus group anonymously using a pseudonym/nickname and you will participate by typing responses so no one will know who you are. No personal information that could identify you will be shared with anyone else besides the research team. To remain anonymous in the focus group, you must not share information in the forum discussions that could identify you to other participants. While we might use quotes from what you have said in reports or publications, no one will know that you have said them.

There are some specific exceptional circumstances where we may need to break this confidentiality: If you share information about crimes relating to the abuse of a minor or vulnerable adult, or crimes relating to terrorism. If we feel that you or someone else is in direct physical danger, we may need to break confidentiality to make sure you or the other person is safe.

## **6. Are there any risks if I take part?**

Participating in the study presents very low physical risks for you, beyond the time commitment involved in doing the interview.

You can choose to share only information you feel comfortable talking about in focus groups. However, if you feel distressed or like you need additional support either during or after the focus group, there will be a member of Salfordautism to offer you support via video call, phone call, or via email.

You can also contact Salfordautism yourself should you require support or information:

Email: <http://www.salfordautism.org.uk>. Call or text helpline: 0771 390 3224

For further information and support you can contact: The National Autistic Society  
<https://www.autism.org.uk/>

## **7. Are there any advantages if I take part?**

The aim of the study is to improve adult social care in England so that it is more responsive to autistic adults' needs, by taking part in the study you will be contributing to this important aim.

To thank you for your time and contribution we will send you a £15 online shopping voucher

#### **8. How will we use information about you?**

We will need to use information from you for this research project. This information will include your name and contact details which will be collected when you agree to participate in the study. Details about your Age, Gender, Sexuality, Race/ Ethnicity will be collected during the interview. We will keep all information about you safe and secure.

People will use this information to do the research or to check 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.

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.

#### **9. What are your choices about how your information is used?**

You can stop participating in the forum focus group at any time, without giving a reason. You can ask us to destroy any information you have provided up until the findings of the study have been published, at which point you will no longer be able to withdraw.

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. All fully anonymised data may be deposited on Manchester Metropolitan University's Open Access institutional repository, the secure e-space (<http://e-space.mmu.ac.uk/>) and may be used for future research and learning.

#### **10. Where can you find out more about how your information is used?**

You can find out more about how we use your information

- At <https://www2.mmu.ac.uk/data-protection/>.
- By asking the lead researcher [m.huysamen@mmu.ac.uk](mailto:m.huysamen@mmu.ac.uk)
- By sending an email to our Protection Officer: [legal@mmu.ac.uk](mailto:legal@mmu.ac.uk)
- Or by ringing the data protection officer at: 0161 247 3331

Focus groups will take place on the discourse platform <https://www.discourse.org/> developed by a company called CDCK. While we have reviewed the Discourse platform carefully and chosen it because its suitability for research, the decision to use the platform remains yours and if you use the platform you will enter into an agreement with the developer. We advise that you review their [privacy notice](#) so that you are aware of how

your data will be used and how you can exercise your rights. Please remember that in order for you to remain fully anonymous on the forums, you should not include any information which may be likely to identify you in the discussions.

### **11. What will happen to the results of the research study?**

The results of the study will be shared with social care stakeholders at workshops and will be used to develop two freely available online digital toolkits (one for autistic adults and one for social care providers) that provide information and resources that can increase understanding and support autistic adults to enjoy fulfilling intimate lives. The digital toolkits and a summary of the findings will be publicly available on the project website and will be shared with those who participate in the study. The results will also be used to write academic journal articles and they will inform presentations and talks.

### **12. Who has reviewed this research project?**

This research project has been reviewed by Health Research Authority (HRA). Ethics Number: 299375

### **13. Who do I contact if I have concerns about this study or I wish to complain?**

For questions about the study, contact the lead researcher, Monique Huysamen, by phone: 07501550535 or email: [m.huysamen@mmu.ac.uk](mailto:m.huysamen@mmu.ac.uk)

If you would like to raise a concern or make a formal complaint to an independent person, please contact: Dr Claire Fox, Faculty Head of Research Ethics and Governance, [claire.fox@mmu.ac.uk](mailto:claire.fox@mmu.ac.uk)