

Multi-disciplinary Evaluation of Sexual Assault Referral Centres for better Health (MESARCH)

Mesarch Cohort Study - Participant Information Sheet (service users)

Why have I been invited to take part?

Thank you for taking the time to read about our project. This project is raising awareness across England about society's response to sexual assault and sexual abuse, and how these experiences affect people's lives, aiming to ensure that individuals who have been affected by abuse get the best care and support possible. If you are 18 years or above and have been to a Sexual Assault Referral Centre (SARC) that is participating in our project, we want to give you a voice. Our project involves inviting individuals with lived experience of sexual assault or abuse into a survey with follow up over two years. The project is called Mesarch and it is funded by the National Institute for Health Research (NIHR).

SARCs across England consider this work important; therefore, we are inviting all service users who attend one of the 15 SARCs participating in our project between August 2019 and June 2020 to be a part of the project.

Do I have to take part?

No, participation in the study is entirely voluntary. Even if you join, you can still withdraw at any time by letting a member of the project team know; email mesarch@coventry.ac.uk, phone 02477659367 or text 07785939958. There are no consequences to withdrawing and you do not have to explain your choice to anyone; staff at the SARC you attended will not be made aware of your decisions to participate or to withdraw.

If I choose to take part, what will happen?

You will be invited to complete a set of questionnaires at 4 points in time over a 2 year period. This can be done over the phone, online via a safe link invite, via Skype, or in-person with one of our trained staff at a time that is convenient to you. The questionnaires ask standardised or structured questions about your health and quality of life, including your mental and sexual wellbeing, your use of services, use of alcohol and drugs. It will ask about experiences of domestic violence in the past and childhood difficulties. However, we are careful *not* to ask questions about the experience that brought you to the SARC you attended on this occasion. At any time, you are free to decline to answer any question that makes you feel uncomfortable but remain in the project. We think that completing the survey will take around 45 minutes to 1 hour. You will have the opportunity to take as many breaks as you wish and should you prefer, you can complete the survey over 2 interviews.

The study will invite you to complete a survey and then to take part in a 6, 12 and 24 month follow-up. We would send you an email, text or phone reminder (depending on your preferences) notifying you that it is time to complete the follow-up. You would be contacted to arrange a time. We can offer a small token of thanks - £10 for each of the first three surveys and £20 at the 2 year follow-up. These will be shopping vouchers which can either be sent to

you via email or posted to you. If you incur travel expenses in order to complete an interview, we will reimburse these.

What are the risks associated with this project?

We will ask you about your health and wellbeing but will not ask questions about the experience that brought you to the SARC. You may still find being asked certain questions difficult. If you feel uncomfortable or distressed at any time during sharing information with us, you are welcome to take a break, skip certain questions, stop the survey completely, or withdraw from the study at any time. We think it is really important that you appreciate the flexibility around your involvement. As your wellbeing and safety are paramount, our study is designed and run with the input of a team of individuals with lived experiences of sexual abuse and assault. At the beginning, the interviewer will make a “verbal contract” with you about what can be discussed and make you aware about how the disclosure of new information relevant to a live case could be called on as evidence in court. Sharing information that indicates there may be an immediate risk of harm to you or a risk to the welfare of a child or vulnerable adult would be grounds for breaking confidentiality.

What are the benefits of taking part?

We would like you to help us understand what works about the services you have received and any changes necessary to help others in the future. You could be joining 1500 other people across the country, contributing to a large-scale evaluation about the extent to which SARCs meet the needs of service users and survivors of sexual violence. This work also has potential to increase understanding about the impacts of violence across the lifespan and influence what is done to support people’s recovery journeys. We hope to improve access to SARCs and other services for individuals with lived experience of sexual assault or abuse and raise the visibility of sexual violence as a widespread problem with devastating effects on individuals, families and communities. With your help, we can make a difference.

Data protection & confidentiality

Coventry University is the sponsor for this study and based in the UK. We will be using information from you and your SARC record 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. Coventry University will keep identifiable information about you until 31/12/2022, unless you consent to being followed-up at a future time, beyond the end of MESARCH, in which case your data will be stored until 31/12/2028. 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. To safeguard your rights, we will use the minimum personally-identifiable information possible. The SARC or ISVA service will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Coventry University and regulatory organisations may look at your SARC and research records to check the accuracy of the research study. The SARC will pass minimal de-identified information collected from you to Coventry University. If you consent to being in the project, this information becomes identifiable to the project. If you decline, it is anonymised. The only people in Coventry University who will have access to information that identifies you will be people who need to

contact you for conducting interviews or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. We will process your personal and/or sensitive personal data in accordance with the Data Protection Act 1998 (“the Act”) and General Data Protection Regulation 2018 (“GDPR”) and keep it confidential. It will be stored in a password protected file at Coventry University. Personal data will be stored separated to other data provided to the project and these sources will be linked by an ID. The Data Protection Act 1998 (“the Act”) gives you the right to access information held about you. Your right of access can be exercised in accordance with the Act. Questions, comments or requests about your personal data can be sent to enquiry.ipu@coventry.ac.uk. Your participation in the research, your personal data and the information you share with our team will not be shared with services you attend or other institutions. The only exception concerns where there is a risk of immediate harm to you, a child or vulnerable adult, or a court orders information collected as part of the research.

What will happen with the results of the study?

The results from the study will be used to help us understand the range of ways in which SARCs impact the lives of individuals who have experienced sexual assault or abuse. These results will be summarised in published articles, reports and presentations and summaries for participants and members of the public will be available on our website.

Who has reviewed this study and what if something goes wrong?

This study has received ethics approval from Coventry University Ethics Committee and the Health Research Authority (East Midlands Research Ethics Committee). Appropriate approvals have also been sought from the SARC and ISVA service you attended. If you have any comments or complaints you wish to raise in regards to how you have been treated, please contact the Pro Vice Chancellor for Research using the address: ethics.uni@coventry.ac.uk.

The team, the funder and where to get further information

Lorna O’Doherty is the project lead. Her work is in the area of mental health and abuse: <https://pureportal.coventry.ac.uk/en/persons/lorna-odoherty>. The project is funded by the National Institute for Health Research and was commissioned because of a recognised gap in understanding about SARC best practice. For enquiries about the project, please contact a member of our team at mesarch@coventry.ac.uk or phone 02477659367 or 02477657470. We also have a project website where you can find out more www.mesarch.coventry.ac.uk.

If you have any concerns about your safety or wellbeing, consider talking to a trusted family member or friend or you could get in touch with the SARC you attended or one of the services listed on our website or overleaf.

Resources you may find helpful:

- **The Survivors Trust: Supporting Survivors of Rape & Sexual Abuse**
For details of specialist support services in your area visit www.thesurvivorstrust.org or for support or advice, call 0808 801 0818
- **24-hour National Domestic Violence Freephone Helpline**
Call 0808 2000 247 or visit www.nationaldomesticviolencehelpline.org.uk
- **MIND – the mental health charity**
Visit www.mind.org.uk
- **Samaritans**
Whatever support you need, call them free on 116 123 or visit www.samaritans.org
- **Male Survivors Partnership**
Please call the helpline on 0808 800 5005 or visit www.malesurvivor.co.uk
- **NAPAC (National Association for People Abused in Childhood)**
Call 0808 801 0331 or visit www.napac.org.uk
- **Childline**
Childline is free, confidential and available any time, day or night. Call 0800 1111 or visit www.childline.org.uk
- **Rape Crisis England & Wales**
For help and support, call the national helpline on 0808 802 9999 or visit www.rapecrisis.org.uk
- **Karma Nirvana**
Supporting victims of honour crimes and forced marriage, call the helpline on 0800 5999 247 9am-5pm Monday to Friday or visit www.karmanirvana.org.uk

You can reach the police on 101 or if you are at immediate risk of harm, please contact the police on 999.



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Thank you for taking the time to read about our project