

Understanding personal shielding experiences: The voices of people living with arthritis and musculoskeletal disease

Participant Information Sheet (PIS) – Creative materials

You are being invited to take part in a research study which aims to understand the experiences of people living with arthritis and musculoskeletal conditions, including rare auto-immune rheumatic diseases, who 'shielded' during the COVID-19 pandemic. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve for you. Please take time to read the following information carefully before deciding whether or not to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. If you would like, one of our team can go through the information sheet with you and answer any questions you have. Thank you for taking the time to read this. We understand you may need some time to think about your decision before deciding whether to take part.

About the research

➤ Who will conduct the research?

We are a team of researchers and patient research partners based at the Centre for Epidemiology Versus Arthritis, University of Manchester. The study is led by Dr Charlotte Sharp, NIHR Clinical Lecturer, and patient partners, Joyce Fox and Lynn Laidlaw.

➤ What is the purpose of the research?

People identified at high risk of severe illness from COVID-19 were labelled as being "clinically extremely vulnerable", and advised to 'shield'. Shielding included being advised to minimise contact with other people, including those within their own households, and only to leave home for medical appointments. People living with arthritis and musculoskeletal disease were amongst those identified as clinically extremely vulnerable and advised to shield.

There has been some research using questionnaires and surveys into people's shielding experiences, which has identified that people's experience of the shielding identification process varied. So far, little research has involved understanding people's experiences using creative materials such as poetry, drawings and photographs. We want explore people's experiences of the identification shielding process and their experiences of shielding, by asking them to share creative materials which might represent their experiences. We hope that this will increase our understanding of the experiences of those who shielded and to generate recommendations to help improve the process if people are advised to shield again in the future.

We are recruiting up to 50 people to submit creative materials. You have been asked to take part because you shielded due to your arthritis or musculoskeletal condition.

➤ Will the outcomes of the research be published?

Our findings will be published in a final report, which will be shared with all participants. We will also publish in academic journals and present at conferences. Any creative materials will be anonymised, unless participants specifically decide that they wish to have their work accredited to them.

➤ **Who has reviewed the research project?**

The project has been reviewed by The University of Manchester Research Ethics Committee, number 2021-11544-20348.

Who is funding the research project?

This project has been funded by Versus Arthritis.

What would my involvement be?

➤ **What would I be asked to do if I took part?**

If you would like to take part, you will be asked to complete a screening survey. The first part of the screening survey includes questions to make sure that you meet the study inclusion criteria. The second part of the screening survey includes questions to help ensure that we will capture shielding experiences from people across a wide range of situations and backgrounds. We will also ask you to share your contact details so that we can discuss your participation and send you relevant documents.

If we invite you to take part and you decide to do so, you will be asked to submit creative materials, via email, within one month of agreeing to take part. We may use these materials as part of the research findings, and include them in reports, scientific papers, online blogs and galleries. Creative materials submitted to this study will become part of the research. This means that the copyright for the work will belong jointly to the University of Manchester and yourself. This means that you may use it for your own purposes, and that they will become part of the research. We will not be able to give the materials back to you, unless you request their withdrawal in the first two weeks following submission.

All creative materials will be anonymised, which means that we will remove any identifying information, and assign the materials a random ID number. We recognise that some people may prefer to be identified alongside their creative materials. You will be given the opportunity to choose to consent to your name being associated with your creative materials. This is optional.

We ask that if you choose to submit a photograph or image containing a recognisable face, that you consent to agree that this will only include images of yourself. If you choose to submit a photograph or image containing a recognisable face, you will be asked to consent to the understanding that by doing so, it could potentially identify you. We will ask for your consent before you send us anything. Verbal consent will be taken over the telephone, and audio-recorded for our records.

Will I be compensated for taking part?

We are very grateful to participants who submit creative materials. We are not offering compensation for the submission of creative materials.

➤ **What happens if I do not want to take part or if I change my mind?**

The study is voluntary and it is up to you to decide whether or not to take part. Please just let a member of the research team know by email or telephone. If you do decide to take part you will be given this information sheet to keep and will be asked to provide verbal consent. Consent will be audio-recorded and stored for 5 years in line with The University of Manchester's research governance policy. If you decide to take part you are free to ask for your data to be withdrawn from the project for up to two weeks after sending us your creative materials. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

Data Protection and Confidentiality

➤ **What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called "personal identifiable information". This information will help us to ensure that we involve a range of different people in our study. Specifically we will need to collect:

- Age category (18-25; 26-35; 36-45; 46-55; 56-65; 66-75; 75+)
- Gender you identify with (male; female; transgender; non-binary; prefer not to say)
- Ethnicity (free text / prefer not to say)
- Rural urban classification (City centre; city suburbs; town centre; town suburbs; large village (>2000); small village (<2000); Hamlet (<100); Isolated house/farm; prefer not to say)
- Geographical location (North East; North West; East Midlands; West Midlands; South East/ East of England; South West; London; prefer not to say)
- Socio-economic status (first half postcode / prefer not to say)
- Employment status (Employed, full-time; employed, part-time; self-employed; volunteer (unpaid work); student; not employed, looking for work; not employed, not looking for work; retired; prefer not to say)
- Musculoskeletal condition / arthritis diagnosis
- Whether or not you shielded
- Contact details, including email address and telephone number
- Audio (sound) recordings of your verbal consent
- All recordings will be taken using a secure, encrypted audio recording device and will be stored on The University of Manchester's secure server.

➤ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

➤ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including transcripts of audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).

➤ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. The study team at The University of Manchester will have access to your personal information and they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. The research team will have access to the key that links this ID number to your personal information.

All researchers are trained with this in mind, and your data will be looked after in the following way:

- All audio-recordings of verbal consent will be recorded using the integrated record function in Zoom and your personal data will be processed by Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the European Commission to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the UK General Data Protection Regulation are in place. The recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection. See Further privacy information: <https://zoom.us/privacy>.
- All audio-recordings will be downloaded onto secure University of Manchester research drives immediately, and deleted.
- All submitted creative materials will be pseudonymised (all personal names and identifying information will be removed and your materials will be given a unique ID code, which is linked to your personal data if needed). Only the research team will have access to the key that links your contact data and ID code.
- All data will be held on secure research drives at the University of Manchester
- The research team at The University of Manchester will keep your information private and only accessible to the research team.
- Creative materials submitted to this study will become part of the research. This means that the copyright for the work will belong jointly to yourself and to the University of Manchester. We will not be able to give the image back to you, unless you request their withdrawal in the first two weeks following submission.
- In refining the research findings, we may share anonymous creative materials with our formally appointed patient and public involvement and engagement group; this would only be done linked to an ID number, unless you specifically request and consent to having your name linked to the work.

- In writing up reports and scientific papers we may share anonymous creative materials; this would only be done linked to an ID number, unless you specifically request and consent to having your name linked to the work.
- In sharing the research findings, we may share anonymous creative materials online, for example in blogs or in an online gallery. This would mean the materials would be in the public domain. This would only be done linked to an ID number, unless you specifically request and consent to having your name linked to the work.
- If you choose to submit a photograph or image containing a recognisable face, you will be asked to consent to agree that this will only include images of yourself. If you choose to submit a photograph or image containing a recognisable face, you will be asked to consent to the understanding that by doing so, it could potentially identify you.
- The audio-recorded consent, and submitted creative materials will be retained for 5 years.
- Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

➤ **Contact details for complaints**

We do not anticipate that taking part in the study will cause you any problems and It is very unlikely that anything will go wrong, but if you have any worries, concerns or minor complaints you can inform a member of the research team first:

DR CHARLOTTE A SHARP, (Principal Investigator)

- Email: Charlotte.sharp@manchester.ac.uk

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#) Tel 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researchers:

DR CHARLOTTE A SHARP (Principal Investigator)

- Email: Charlotte.sharp@manchester.ac.uk

LYNN LAIDLAW (Patient contributor)

- Email lynn.laidlaw@manchester.ac.uk

JOYCE FOX (Patient contributor)

- Email: joyce.fox@manchester.ac.uk

Are there any additional considerations that I need to know about before deciding whether I should take part?

We realise that shielding and people's experiences of the COVID-19 pandemic have been challenging. In the event that you feel distressed after submitting creative materials, please contact one of the following organisations for support.

Mind

Lines are open Mon-Fri 9-6pm, except for bank holidays

Infoline: 0300123 3393

Text: 86463

Email: info@mind.org.uk

Samaritans

National helpline: 116 123 (24 hours a day, 365 days a year, free to call, at any time, from any phone

Email: jo@samaritans.org

Manchester and Salford Samaritans

Address: 72-74 Oxford St, Manchester, M1 5NH.

Telephone: 116 123 free from any phone

0330 094 5717 (local call charges apply)

Versus Arthritis

National helpline: 0800 5200 520 (Monday to Friday, 9am-6pm).

Email: helpline@versusarthritis.org