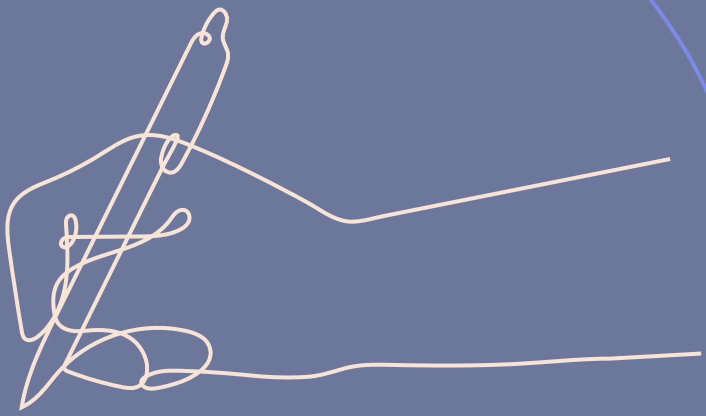
MODERN SLAVERY & HUMAN RIGHTS | POLICY & EVIDENCE CENTRE
Led by the University of Oxford

Navigating the ethics of research participation

Guidance note 3



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Who is this document for?

In this document we answer questions commonly asked by participants when they get involved in research for the first time. It gives particular attention to issues that might concern people with lived experience (LE) of modern slavery and human trafficking.

What is this guidance based on?

This guidance note draws on the findings and recommendations of a study commissioned by the Modern Slavery and Human Rights Policy Evidence Centre, which are available to read in full within the project's published report. This project examined approaches to ethics in the field of modern slavery research. It aimed to identify good practice in embedding ethical survivor engagement within projects asking what is currently working well and where can improvements be made. It focussed on practice in the UK context.

This guidance note (GN3) is accompanied by two others – 'Promoting ethical governance of MSHT research' (GN1) and 'Conducting co-productive research ethically' (GN2).

Content Notice: This guidance note does not discuss in detail any explicit/sensitive topics. Some of the content will, however, refer to topics relating to slavery, servitude, human trafficking, forced labour, forced marriage, child marriage, conflict and forced migration.

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1. What are research ethics? Why does this matter?

Research ethics are principles and processes that regulate the practice of researchers. The purpose is to ask researchers to reflect on how they conduct their research, considering the scope for their work to benefit or potentially harm those involved.

Ethics review and safeguarding policies are examples of research ethics in practice. These processes are designed to ensure researchers embed values such as care, honesty, respect and equity within their work. They also aim to maximise benefits and minimise harms for all involved in research. If potential harms are identified, researchers must have plans to lessen and prevent these harms. Ethics frameworks also ask researchers to reflect on the scope for those involved in research – including participants – to exercise choice and be treated fairly.

These considerations are of particular importance when researchers are planning to do participatory work – that is producing research with affected individuals or communities. In these cases, ethics review processes are compulsory for researchers within universities. These review processes are designed to promote positive experiences for all involved in research.

2. What is a Research Ethics Committee (REC)?

A Research Ethics Committee (REC) is a group of researchers who have been appointed or volunteered to review research projects at their institution. In the UK, research projects that plan to involve any human participants in their work must be reviewed and approved by a REC.

Ethics review includes questions on the aims and design of the project, how participants will be selected, approached, and the ways they will be involved. Researchers are expected to share how they will minimise and prevent harms to participants and protect and store any data that will be collected. This process should help researchers embed good principles for proper conduct of their research in their project plans. It should also help research teams identify current best practices to inform their approach to work with participants.

Research teams will be asked, by their REC, to produce a Participant Information Sheet. This document provides details that will enable participants to make an informed choice about being involved.

3. What is a Participant Information Sheet and what is it for?

A Participant Information Sheet is designed to share key information about project plans with participants so that they can make an informed choice about whether to take part. It will include information on the aims and focus of the research project, anticipated benefits and risks to participants, safeguarding contacts, data collection and storage protocols including information about confidentiality and anonymity, as well as participant withdrawal processes (what a participant can do if they want to stop taking part in a project).

The Participant Information Sheet should also include information such as the application review number and contact details for the lead researcher as well as the reviewing Research Ethics Committee (REC). This is so that participants can ask questions or raise concerns before deciding to take part.

4. What is a research participant? Who can be one?

A research participant is someone who voluntarily agrees to take part in a research project. They may be invited, or they may have responded to an advertised request. Most often participants are invited to take part in a study because they belong to a group or community that shares a characteristic, attribute or experience which the study aims to learn more about. In research on modern slavery, human trafficking (MSHT) and exploitation this is likely to be someone who agrees to share their knowledge, expertise and/or lived experience through interviews, surveys, or focus groups.

5. Can lived experience experts take up other roles in research?

Currently within research related to MSHT, lived experience experts or survivors are increasingly invited to take up professional roles as peer-researchers and research consultants or as members of advisory boards and panels. For more on best practices of peer-researcher or consultant engagement in research see GN2.

A peer researcher or research consultant is: a member of the research team, directly contributing to the research project. Often LE experts in these roles are experienced in conducting research themselves or from an academic background. They may also provide advocacy and support to LE participants.

An advisory group or panel member is: less likely to provide direct input or be considered part of the research team but will instead provide added value through oversight, regular feedback, offer guidance and advice on a particular project or to an organisation.

6. What can I expect in terms of payment or reimbursement for research participation?

You should expect to be compensated for your involvement and for time spent engaging on any research project. How you will be compensated may vary from project to project. It should be noted that different compensation methods have different implications for participants. For those without right to work, or who have limitations on what they can earn due to being in receipt of legal aid, benefits or other support it is important to seek specialist advice before taking part in research and receiving any payment to avoid adverse impacts. Best practice is for research teams to offer you flexibility in methods of compensation for your research participation. Options may include payment by BACS or bank transfer, in cash or by voucher. Some payment methods may involve your data being shared with a third party such as HMRC. It is important you speak with research teams about compensation prior to your involvement and check whether this involves your information being shared with any third parties.

In taking up a professional role – such as peer-researcher, consultant or advisory board member – lived experience experts should receive fair and appropriate payment for the work that they undertake. These payments are likely to be considered as earnings and may therefore have tax and other implications for the lived experience expert receiving them. Again, it is important to seek specialist advice before undertaking these roles if you have limitations on the level of earnings you can receive.[1]

7. What can I expect in terms of support?

Engaging in research, especially on sensitive issues, can sometimes bring up difficult or distressing memories. To support participants, researchers should provide clear information on accessing trauma-informed support. This may include information about counselling services, hotlines, or other mental health support options that can be accessed during or after participation.

In some cases, researchers may arrange for clinical professionals, such as trained counsellors or therapists, to provide follow-up support. If you are unclear about whether this support is offered, you can ask before you begin taking part. These details may be included in the project's Participant Information Sheet.

8. Can I request access to a translator or interpreter?

If English is not your first language and you would struggle to read the Participant Information Sheet without support from a translator, you should tell the research team. It is crucial that you fully understand the information provided so that you can give informed consent to take part. Depending on project budgets and resourcing available, research teams may be able to provide access to a translator or interpreter to support your involvement in the project. Translators and interpreters should be impartial and provided through a trusted partner.

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[1] More detailed advice on payment implications (particularly in the UK context) can be found at: NIHR. (2024). Payment guidance for researchers and professionals. Accessed 17 December 2024; SCIE (2023). Paying people who receive benefits: Co-production and involvement. Accessed 17 December 2024; Scottish Government (2024) Guidance: paying participant expenses and compensating for time. Accessed 17 December 2024.

9. What happens if I share sensitive information?

If you share information that raises concerns about immediate risk of harm to yourself or another person, the researchers you are working with may be required to report this to a safeguarding officer within their organisation or to another relevant authority. In addition, researchers are required to report on certain crime-related risks to participants.[2]

If you share information related to these risks/activities this is often called a 'disclosure'. If you make this type of disclosure during research the confidentiality of the information you have shared may not always be assured. If you are not sure what the disclosure requirements are for any research team/researcher you are invited to work with, you can ask them to tell you this in advance of sharing any information.

Being clear about this is particularly important if you have ongoing and complex legal proceedings or have a case moving through the asylum system. Understanding the disclosure obligations and protocols of any research team you are working with will help minimise the risk of you sharing information which may impact you negatively through unsolicited social service or police involvement.

If you share information that you consider sensitive, but which is not considered a 'disclosure', and you later decide that you would like the researcher not to include this in their study or any publications, you have the right to withdraw this information. There are usually limits to withdrawal (for example, once data has been anonymised or published and if you've taken part in certain activities such as a focus group). Details about these limitations should be outlined in the Participant Information Sheet, where instructions about how and when you can withdraw from a research project will also be given.

10. What is a distress protocol?

Distress protocols offer guidance on when a researcher should intervene if a participant or fellow researcher appears to be distressed, or reports feeling distressed, during a research activity such as an interview or focus group. Guidance often suggests how to sensitively pause activities, when to check-in with anyone potentially experiencing distress, how to signpost support and when to follow-up. The distress protocol should be available on request before you engage in the project.

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2. In the UK context this includes: an act of terrorism; acts of treason; suspected instances of money laundering, and information about the neglect or abuse of a child or at-risk adult.

11. What happens to my data after I take part in research?

In this context, data is any information such as facts, opinions, observations or statistics gathered by a research team during a study. Your data might be collected through an interview, focus group, online survey, workshop or another activity.

Should you consent to take part in research, ethical research projects will ensure your data is handled with care and respect. Your data will be stored securely, and strict guidelines will be followed to protect your privacy (more details on this should be provided in the Participant Information Sheet for specific projects). Researchers should clearly outline how your data will be used, where it will be stored, how long it will be stored for and how it will be disposed of. If you change your mind about participating, you may request to withdraw your data within a time period that is specified by the research team (often within a few weeks of data being collected).

12. Will there be a chance for me to review the data I have shared with researchers before it is published?

It is good practice for researchers to offer a clear timetable for any participants to review the data (or information) they have shared during a project and have the opportunity to offer feedback on its interpretation before their research findings are published. Reviewing your data at this stage helps to ensure your contributions are accurately recorded, and that your voice is authentically reflected in the research project's findings. It is advisable to inform the research team should your contact details change so that you can be kept informed.

Once you have had a chance to review your contributions, the research findings will be shared through a range of 'research outputs' including publications (such as books, articles or reports), presentations and on webpages. Information on where these findings will be published should be made available to you. If you have any concerns about this you should raise it with the research team before participation, if possible, and in advance of publication.

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HUMANITIES DIVISION

The Modern Slavery and Human Rights Policy and Evidence Centre (PEC) at the University of Oxford exists to enhance understanding of modern slavery and transform the effectiveness of laws and policies designed to address it. The Centre funds and co-produces high quality research with a focus on policy impact, and brings together academics, policymakers, businesses, civil society and survivors to collaborate on solving this global challenge.

The Centre is a consortium of three Universities of Oxford, Liverpool and Hull, and is funded by the Arts and Humanities Research Council (AHRC) on behalf of UK Research and Innovation (UKRI).

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