



Study title: **Safeguarding Adults for Empowerment (SAFE project)**

WP1 (2): Interviews. (IRAS ID: 329360).

What is the Purpose of the Study

This project aims to improve adult safeguarding by developing knowledge and understanding of this area. Adult safeguarding is work that is done to protect people's rights to live in safety, free from abuse and neglect.

We will be exploring this by speaking with people who have experiences of adult safeguarding in different ways.

You are being invited to take part in this research study. Before you decide whether to participate, it is important for you to read this leaflet so you understand why the study is being carried out and what it will involve.

Reading this leaflet, discussing it with others, or asking any questions you might have will help you decide whether or not you would like to take part.

You can request an audio copy of this information sheet, or request it in a different language, by emailing Keith Chappell (research associate at the University of Sunderland):
Keith.chappell@sunderland.ac.uk

Why have I been invited?

We are interested in talking to you if you are over the age of 65 and would like to share your views and experiences of adult safeguarding. To take part you should:

- Be over the age of 65
- Have been through adult safeguarding (after 2015)
- Have capacity to take part in the research

If this does not apply to you then you can disregard this information sheet.

Do I have to take part?

No. It is up to you whether you would like to take part in the study. We are giving you this information sheet to help you make that decision. You can discuss this with someone or speak to us to ask questions before you decide.

If you do decide to take part, remember that you can stop being involved in the study without telling us why. You are completely free to decide whether to take part, or to take part and then leave the study before completion. If you decide to take part then you will have two weeks from the date of your interview to change your mind. If you let us know within this time period then we will remove your data from the study. After this point it may not be possible to identify and remove your data.

If you do not wish to take part then please disregard this information sheet. Please feel free to contact us to ask questions or have a chat about the research using the email address or telephone number provided below.

What will happen if I take part?

We understand that this is a very sensitive topic to discuss with other people and we would like to reassure you that the research will be conducted in a way that is sensitive and that you will not have to share any information that you do not wish to. We are interested in exploring with you your experiences of adult safeguarding.

If you choose to take part in the research, you will be invited to take part in an interview with a member of the research team. Each interview will last approximately one hour. It will be arranged for a time and place to suit you and can take place face to face or online, depending on your preference.

Before the interview there will be an opportunity for you to ask questions and we will establish together some rules for the time together (for example, around confidentiality or subjects you wish not to discuss). You will then be asked to sign a short form which indicates that you agree to take part in the research.

We will ask you about the following things:

- Your initial referral into adult safeguarding
- Your awareness and understanding of adult safeguarding and what it means to you
- Decision making – when and how you were able to make decisions about what happened
- What you wanted from safeguarding and whether this was achieved
- Your sense of control over what happened
- What support you wanted, were offered, or received
- Whether you were given an opportunity to feedback to the safeguarding team about your experience
- Your overall experience

You will be able to respond in ways that you feel comfortable with. This may include short answers, longer stories or giving examples. Depending on your answers we may also ask other questions to follow up on what you say. We will not ask you anything about the experiences of abuse or neglect that brought you into adult safeguarding – only about what happened after it was reported.

It is also important that you understand that your involvement in the research is voluntary and that if you decide to take part you can change your mind at any time without having to give a

reason and without it affecting any services you may be receiving. You can withdraw from the study at any point up until two weeks after participation in the interview. After this point it may not be possible to identify and remove your data.

There will be opportunities to take a break whenever you want to during the interview. You can also bring someone with you to the interview, if you want to.

The interview will be conducted by a member of the research team. This will probably be Keith Chappell, but he might be accompanied by another member of the research team. If you prefer for Keith to interview you alone or to be interviewed by a female member of the research team please let us know. Likewise, if you need any other arrangements to be made to support your involvement, please let us know using the contact details below.

The interviewer will make an audio recording of the interview and will take notes based on the conversations. They will ask your permission before doing so and these will not record any notes that would mean you could be identified. We will also ask you to fill in a short survey which will ask for some information about yourself, e.g. gender, age, ethnicity etc.

Everything that you say is confidential unless you tell us something that indicates that you or someone else is at risk of harm. This would be discussed with you before telling anyone else.

We may contact you after your participation to ask some follow-up questions. If you would prefer us not to do this you can tell us during or after the interview using the contact details below. We will only contact you within six weeks of your participation to ask for additional information.

What are the possible disadvantages of taking part?

We understand that discussing this topic with us may be difficult for you. We will give you some information about services you can access for support, should you need this.

We would like to reassure you that you can opt out of the research at any time up until two weeks following your interview, by stopping the interview or by letting us know during or after the interview.

We also understand that taking part in this research means that you are giving up your time to be involved and that you may experience some costs (e.g. travel or personal assistant (PA) support time) to be able to take part. If you choose to take part then we will cover your travel and/or PA expenses (you will need to provide us with a receipt). We will also offer you a £20 Amazon voucher as a thank you for your time.

What are the possible benefits of taking part?

By taking part in this study, you will be helping us to improve adult safeguarding to ensure that people are listened to and able to make decisions about what they need to be safe. Generating a greater understanding of this area will help us to improve responses and services.

Will my taking part in this study be kept confidential and anonymous?

Yes. All of your personal information will be kept confidential, but things that you tell us in the interview will be shared via various means (detailed below). Any information that is shared in

these ways, including any direct quotations from you, will be fully anonymised first. This means that you will not be identifiable from this information; your name will not be used in any of the information that is shared. Your name will also not be written on any of the data collected.

The written information will have a pseudonym, not your name. Your name will not be written on the notes taken, or on the typed-up versions of the interview. Nor will it appear in any documents or reports resulting from the study. The consent form you sign will be kept separately from your other data.

How will my data be stored, and how long will it be stored for?

Your consent forms and any other paper data will be copied to a computer where possible and stored on the university drive which is password protected. Any paper documents will be kept in a locked cupboard in a restricted access room. Recordings and typed up versions of the interview will be kept securely on the university system and will be password protected and anonymised. Any electronic data will be stored in the university drive, which is password protected. All data will be stored in accordance with university guidelines and General Data Protection Regulations (GDPR). All personal data will be deleted 6 weeks after you have taken part in this interview, unless you have given us separate permission to keep your contact information for a later event (in which case it will be deleted 6 weeks after that event).

What categories of personal data will be collected and processed in this study?

We will collect some key personal information which will be collected and stored anonymously. We will also collect your name on the consent forms. This will be stored separately from your anonymised data. If you wish to receive information about the findings of the research then we will also need to collect your contact details. There will be a space on the consent form to request this information and to provide your details. This information will be stored as detailed above.

What is the legal basis for processing personal data?

The legal basis for processing personal data required for the purposes of this study is Article 6(1) of GDPR, processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested the controller.

Who are the recipients or categories of recipients of personal data, if any?

Only the research team will be working with your identifying personal data. Anonymised personal data (e.g. age, gender, ethnicity) will be shared as detailed below.

What will happen to the results of the study and could personal data collected be used in future research?

The anonymised general findings (including recordings and transcripts) from this research may be reported in a scientific journal, presented at a research conference and shared with the research funder. It may also be used in teaching, shared on social media, or used in other ways, such as included in blog posts or stored in a data archive. We will also use anonymised findings from this research at a co-production event towards the end of the study. You are welcome to attend this

event – please speak to one of the research team to book a place and find out more.

However, the data will be anonymised and you or the data you have provided will not be personally identifiable. The anonymised findings may also be shared with other organisations/institutions that would benefit from the study findings. We can provide you with a summary of the findings from the study if you tick the appropriate box on the consent form and provide your contact details.

A later stage of this study will involve interviewing people who provide support services to older people and we plan to use the anonymised information gained with you to inform that part of the study. This will be used to help form the questions used and to use experiences shared in this stage to stimulate responses from these people.

We are collaborating with the organisation Made by Mortals who create audio and video productions based on lived experiences. The stories they tell are inspired by real life stories but do not contain details of individual's lives. We plan to share the anonymous information gained through this study with them to help us produce an audio story that will help people such as social workers and policy makers understand more clearly the experiences of older people. No audio or video recordings of you, or photographs of you, will be used. If you would like to take part in creating the audio case studies you can contact Made by Mortals by emailing:

Paul Hine (Chief Executive of Made by Mortals) paul@madebymortals.org

Made by Mortals will then provide additional information and seek separate consent for you to take part.

Who is Organising the Study and who is part of the research team?

This study is being led by a team from the University of Sunderland.

- Dr. Sarah Lonbay (Associate Professor at the University of Sunderland) is organising the study.

The other members of the research team are:

- Dr. Keith Chappell (University of Sunderland)
- Dr. Carole Southall (Northumbria University)
- Jamie Scorer (University of Sunderland)
- Martin Wilkes (University of Sunderland)
- Ilene Byrne (University of Sunderland)
- Claire Nixon (Newcastle City Council)
- James Babyk-Glynn (Oldham Council)
- Professor Toby Brandon (Northumbria University)

Interviews will be carried out by Dr Keith Chappell. At times he may also be supported by another member of the team.

This project has been funded by the National Institute for Health and Care Research (NIHR)

Research for Patient Benefit (Research for Social Care call): NIHR205704.

Who has reviewed this study?

The study has been approved by the Health Research Authority research ethics committee (IRAS ID: 329360). The study has also been reviewed and approved by the University of Sunderland Research Ethics Group (ethics reference number: 027527).

What are my rights as a participant in this study?

You have the following rights as a participant within this study:

- a right of access to a copy of the information comprised in your personal data (to do so you should submit a [Subject Access Request](#));
- a right in certain circumstances to have inaccurate personal data rectified;
- and a right to object to decisions being taken by automated means.
- If you are dissatisfied with the University's processing of personal data, you have the right to complain to the Information Commissioner's Office. For more information see [the ICO website](#).

What should I do if I need support?

If you need any help to allow you to take part in the study please ask Sarah or Keith (details below) and we will try to provide any support needed.

If taking part in the study raises any issues that you feel you need support or guidance with you can contact one of the organisations listed at the end of this information sheet. Members of the team are also available to talk with and you can call or email us using the details below, we will try to guide you to the best support for you.

If you share with us information that indicates that there is a significant risk of harm to you or someone else, we may have to share that information with relevant people who can help, such as social services or the police. We will discuss this with you first before we share the information with anyone else and help you to share it yourself with these organisations if you would prefer.

What should I do if I want to take part?

If you would like to participate in the study then please contact Sarah or Keith using the details below.

Please also feel free to get in touch if you have any questions or would like to chat about the study.

Contacts for further information and to take part:

For more information about the project, or to take part, contact:

Dr Keith Chappell

Email: Keith.Chappell@sunderland.ac.uk . Tel: 07354 481606

You can also contact Dr. Sarah Lonbay (Principal Investigator) for more information about the project:

Email: Sarah.Lonbay@Sunderland.ac.uk/ Tel: 0191 5252153/ M: 07811770678

Link to profile: <https://www.sunderland.ac.uk/about/staff/social-sciences/sarahlonbay/>

If you have any concerns about the conduct of this study, please contact Dr Matt Campbell (Chair of the University of Sunderland Research Ethics Group, University of Sunderland): Email: Matthew.Campbell@sunderland.ac.uk

For more information about the audio case studies, or to get involved in their creation, please contact Paul Hine (Made by Mortals) via email address paul@madebymortals.org.

If you feel that you would like support with any issues you may find some of the links and numbers below helpful:

National Domestic Abuse Helpline: 0808 2000 247 or www.nationaldahelpline.org.uk

Adult Safeguarding, Newcastle City Council: 0191 278 8377

Adult Safeguarding, Oldham Council: 0161 770 7777

(In an emergency or if you think someone is in danger call 999 and speak to the police.)

For support on a wider range of issues you can find a number of services here:

Hub of Hope www.hubofhope.co.uk (this website will provide links to services available in your area)