

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number:

Title of project

Survivor Exploration of Meaning, Articulation and Negotiation of Terminology and Identity in Complex trauma (SEMANTIC)

Invitation

We would like to invite you to participate in the SEMANTIC study, led by King's College London in partnership with Traumascapes. Before you decide whether you would like to take part, it is important that you understand why this research is being done and what your participation will involve. Please take the time to read the following information carefully. You can discuss it with others if you would like to and you are welcome to ask us if there is anything that is not clear, if you have any questions, or if you would like a chat with us.

What is the purpose of the project?

This project is a collaboration between researchers with lived experience of trauma, violence and abuse. The purpose of the project is to explore the terminology that people use to describe themselves as people with lived experience of violence, abuse and trauma, such as 'survivor', 'victim', 'victim-survivor', 'wounded', or other terms, or a rejection of labels altogether. We are also interested in the connection between our identities, relationships and healing journeys and the language we use. We will explore this in interviews with people who use lived experience of trauma, violence and abuse in their research, art or activism. We will then hold a focus group to make sure that we have understood what we were told and to try to agree key points.

We would like to use the findings to guide the terms that researchers and artists use when we carrying out research and/or art projects with people with lived experience of trauma, violence and abuse. Although finding a single term that everyone agrees on might not be possible, we hope to gain further insights into our community's preferred terminology and explore contextual differences.

Why have I been invited to take part?

You are being invited to participate in this project because you have lived experience of trauma, violence and/or abuse which you use in your work - either in research, art, activism or a combination.

What will happen if I take part?

If you choose to participate in the project, you will be asked to take part in one interview. The purpose of the interview is to understand what terminology you use to refer to your lived experience of trauma, violence and abuse, and why. Then, people who took part in the interviews will be invited to an optional focus group where we will present our findings, hear your feedback, make changes or additions, and see whether we can jointly agree on the key points. The purpose of the focus group is to make sure that we are summarising and analysing what we were told in the interviews in the best way.

The main research question we seek to answer through the interviews and focus group is: 'How does the terminology people use to describe their lived experience of violence, abuse, and trauma connect to their identities, relationships, and healing journeys?'

Our objectives are to;

- Explore which terms people use (or refuse) to refer to having lived experience of violence, abuse, and trauma, in what context, and why;
- Explore how people identify with different terms;
- Consider arguments for and against the use of different terms in research, art, or activist practice

Here are the key points about the interviews:

- Interviews will last approximately 1 hour, depending on how much you would like to say.
- Interviews will be conducted in English, though you may request to be interviewed by a researcher who also speaks French or Portuguese.
- You may choose whether you would like to be interviewed by a man or a woman.
- All researchers in our team have lived experience of violence, abuse and trauma.
- We will offer you a choice between an online or in-person interview. In-person interviews will be held either at King's College London (SE5 8AB), at Traumascapes (E2 8HD), or in a public setting, based on your preference.
- The kinds of questions we will ask in the interview include 'What terms have you or others used to refer to you as someone with lived experience of trauma?', 'Can you tell me about the terms you identify with?', 'How do the terms you use relate to your healing journey?'. You will be offered interview topics / questions in advance. This might help you to decide whether or not you want to take part, or whether there are questions you do not wish to answer.
- You will also be asked some questions about yourself, such as your age, gender identity and sexual orientation. All of these questions are optional, which means that you do not have to answer some or all of them.
- If you consent to it, interviews will be audio-recorded. We will use an automatic transcription service (e.g. otter.ai, Adobe Premiere Pro, or Apple Dictation) to create a written copy of your interview. We will listen again to your interview to make sure the transcript is correct, and we will then delete the audio-recording. If you do not consent to the interview being audio-recorded, hand-written notes will be taken instead. You will be offered a copy of the transcript (or notes) and invited to make changes or send further comments if you wish to (this is optional).
- We will use reflexive thematic analysis to understand the information we gather through the interviews. This method allows us to outline the key themes within and across

interviews so that we can gain an in-depth understanding of the different ways people who use lived experience of violence, abuse, and trauma relate to the terminology used to describe that lived experience.

- The transcript of your interview will be anonymised, which means we will take out any details that might identify you. This transcript will not be shared with anyone outside of the research team.
- The interviewer will keep what you say confidential, only sharing information with the research team. However, if the interviewer is concerned about a significant risk of harm because of something you share, they have a responsibility to take action. Significant risk of harm includes current physical, sexual or emotional abuse, suicidal feelings or intent, or life-threatening levels of self-harm. We will first talk to you and will aim to agree actions with you.

Here are the key points about the focus group:

- The focus group will be held online using Zoom.
- The focus group will last approximately 2 hours, with a break.
- Everyone who took part in the interviews (12 to 18 people in total) will be invited to join the focus group if they would like to.
- People who wish to take part in this second stage but would rather have a 1:1 conversation instead of joining the focus group will be offered this option.
- The kinds of questions we will ask in the focus group include 'Do the themes we have identified from the interviews reflect your perspectives?' and 'Is anything missing?'.
- The focus group will also be audio-recorded. We will use an automatic transcription service (e.g. otter.ai, Adobe Premiere Pro, or Apple Dictation) to create a written copy of the focus group. We will listen again to the focus group to correct any errors in the transcript, and we will then delete the audio-recording. All participants will be offered a copy of the transcript (this is optional).
- The outcomes of the focus group will help shape our thematic analysis and define the final outcomes of the study.
- Please note that the interviewer will keep what you say confidential, only sharing information with the research team. Once again though, if they are concerned about a risk to life from something that is shared, they have a responsibility to take action. As for interviews, they would first speak with the person who shared this information to try to agree a way forward.
- Please remember that everyone attending the groups should maintain confidentiality. If you are concerned about someone else from something you have heard, please speak with a member of the research team.

Once we have finished writing up the study, and if you agree, we will send you a report written for participants so that you can find out what we learned through the study.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to. Choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What are the incentives to taking part?

You will be offered £25 either as payment or as a voucher, as preferred, for taking part in the interview. You will be offered a further £25 if you choose to take part in the focus group. This is to thank you for your time and contributions.

What are the possible benefits of taking part?

There are no direct benefits to participants, though we hope that our findings will be useful to you and your work as we will gain insights into our community's preferred terms which may guide the language we use in our practices focused on violence, abuse, and trauma.

What are the possible risks of taking part?

Though we will not discuss your lived experiences of violence, abuse, and trauma, talking about terminology related to these can still be upsetting. We encourage you to carefully consider whether this is right for you at this time. We can offer you a copy of the interview and focus group questions to help you decide whether you want to take part, if you would like this. If you do decide to take part, you can let us know if there are questions you do not wish to answer. You can also stop the interview at any time to take a break, or to end the interview.

Taking part in the focus group is entirely optional. We will share safety guidelines with you before you attend the group, and will remind people of these at the start of the group. You can also leave the focus group at any point, turn your camera off, and refuse to answer any question at any point without having to give a reason. We will send you information about safety, self-care and sources of support before and after the focus group.

What if I want to access support?

If you need support at any time, you can access help through the following sources:

Samaritans: Free call service for mental health support, 24 hours a day (www.samaritans.org.uk, call them on 116 123).

Survivors Voices: peer support groups for abuse survivors (www.survivorsvoices.org)

Little Ro: support groups for BIPOC and global majority people (www.littlero.org)

NAPAC: support line for adults who have experienced any form of abuse as children (www.napac.org.uk)

NSPCC: support for children at risk of abuse and their families (www.nspcc.org.uk)

Stop it Now: for anyone concerned about child sexual abuse (www.stopitnow.org.uk; 0808 1000 900)

Survivors Trust: helpline and network of organisations supporting survivors of sexual violence

(www.thesurvivorstrust.org; 08088 010818)

Into the Light: support for people who have been sexually abused (www.intothelight.org.uk)

Respect: support for male victims of domestic abuse (www.respect.uk.net)

Safe Spaces: support for people abused within the Church of England, Catholic Church in England and Wales, or the Church in Wales (www.safespacesenglandandwales.org.uk)

MIND: information and help with mental health (www.mind.org.uk)

It's good two talk: finding a registered therapist (www.itsgoodtwotalk.co.uk)

Trauma Action Group: trauma and abuse education and resources (www.tagtrauma.com; hello@tagtrauma.com)

Data handling and confidentiality

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018). All information will be kept in secure online storage repositories, and will only be accessed by the research team. We will not share data or information with anyone who is outside of our research team. The audio recording of the interviews and focus group will also be kept in secure, online storage and will be deleted once a transcript has been created.

We will make sure that no-one can be identified in any publications about this study. While we may use quotes from the interviews and focus group, we will make sure that it is not possible to identify anyone from these quotes. We will hold your anonymised data, securely, for ten years following the end of the research study in line with the principles of the Data Protection Act (2018). This is in case we need to contact you about the study, or if you have any questions for us about your involvement in the research. Any information that could identify you will be destroyed upon completion of the project.

King's College London has a responsibility to keep information collected about you safe and secure, and to ensure the integrity of research data. Specialist teams within King's College London continually assess and ensure that data is held in the most appropriate and secure way.

Data protection statement

If you would like more information about how your data will be processed under the terms of UK data protection laws please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

If it is difficult for you to access this through the link above, you can request a printed copy.

What will happen to the results of the project?

The transcripts will not be made publicly available. We will share the findings in the following ways:

- We will write up a short and accessible report for the people who took part in the study.
- We will share the findings through a creative output.
- We will share the findings in an academic paper.
- The Traumasclapes Arts Collective will create artwork that responds to the findings. You can find out more about the artists [here](#) and can explore their work on survivorhood [here](#).
- We may also produce a blog about the study.
- We may speak about the study and our findings at conferences and events.

What if I change my mind about taking part?

You are free to withdraw from the project at any point up until August 2024, without having to give a reason. Withdrawing means that we will not retain your interview transcript or any other information you gave us about yourself. Withdrawing from the project will not affect you in any way. After August 2024, withdrawal of your data will no longer be possible as the findings will have been written up. However, if you contact us before we publish the findings, we will try to remove any quotes from you in the write-up.

Withdrawing what you said from the focus group transcript is more complicated because it is not always possible to tell who is speaking. If you contact us before August 2024, we will do our best to remove your comments. Alternatively, you can let us know which comments you would like us to remove. After August 2024, withdrawal will again no longer be possible as the findings will have been written up. However, we will try to remove anything that you said from our write-up if you let us know before publication.

How is the project being funded?

This project is being funded by the ESRC Centre for Society and Mental Health at King's College London: <https://www.kcl.ac.uk/csmh>

Who should I contact for further information?

If you have any questions or require more information about this project, please contact Angie Sweeney using the following contact details:

angela.sweeney@kcl.ac.uk
Institute of Psychiatry, Psychology and Neuroscience
King's College London
De Crespigny Park
London, SE5 8AF

What if I have further questions, or if something goes wrong?

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project you can contact King's College London using the details below for further advice and information:

The Chair
The Health Faculties Research Ethics Committee
King's College London
rec@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this project!