



Participant Information Sheet
UCL Research Ethics Committee Approval Number: 26367/001

Understanding Self-Harm in Young Autistic People

**Trigger Warning – this information sheet may contain triggering and/or sensitive material. Self-harm is mentioned in this information sheet. **

We are inviting you to take part in a research study.

This information sheet provides the relevant information to help you to decide if you would like to take part in our research study.

Please take the time to read and think about the information provided. It is important that you understand what the research study is about and what you will be asked to do if you take part. If you do not understand any information or would like more detail about the research study, please contact the research team. We are happy to answer any questions that you may have to help you decide whether you would like to take part.

You might also want to share this document with family members, friends, or other people who support you, to help you decide.

Why are we doing this research project?

Some autistic young people have difficulties with their mental health. This can include self-harm (e.g., when someone hurts themselves on purpose).

We want to increase our understanding of self-harm in young autistic people. We want to learn about their experiences, the factors that increase or reduce the risk of self-harming, and the impact of self-harm on young autistic people, their families, and wider social relationships.

At present, we know little about the experiences of young autistic people who self-harm. If we understand this better, we can increase awareness and think of new strategies to improve the mental health and wellbeing of young autistic people.

Why have my child and I been asked to take part?

We are inviting you to take part in this research because you (or your parent) contacted us after seeing an advert for the research study.

We would like to recruit young people who are autistic, aged between 10 and 24 years old and have some experience/history of self-harm, to take part in the study.

We would also like to recruit parents/carers of autistic young people with experience of self-harm. With your permission, we would like to ask your parent/carer if they would like to participate in the research study.

Do I have to take part?

No, it is entirely up to you.

If you decide to take part, you can change your mind and leave the study at any time, without giving a reason or repercussions. In addition, you can also choose not to answer any question, take a break, or end the interview at any time, without giving a reason or repercussions.

If you decide not to take part, any care or support you currently receive, will not be affected.

What will I have to do if I agree to participate in an interview?

We will arrange a short online introduction meeting with one of our researchers, which will last about 15 minutes. You can be at this meeting alone or with your parent, it is up to you.

At this meeting, the researcher will introduce themselves and answer any questions that you have about the research study. The researcher will also ask you some questions about your past and current mental health, to check if you have experience of self-harm and are eligible to take part in the research study.

If your responses show that the research study is not suitable for you, we will let you know as soon as possible and delete any personal information that we hold about you (e.g., name, contact details).

If you do meet the criteria to take part in the research study, the research team will get in touch to arrange a time and date for the interview.

What will happen during the interview?

You can choose how and when you would like to do the interview. You can decide to do the interview online by video call (e.g., Microsoft Teams or Zoom). Or, if you would prefer to meet with the researcher in person, they can come to your home or arrange for the interview to take place at UCL. The interview will last about 1 hour.

In the interview, the researcher will ask you questions about how you experience being autistic, your mental health including your experiences of self-harm, the factors that increase or reduces the risk of self-harm (e.g., what stresses you out and what makes you happy), and the impact of your self-harm on you, your family and wider social relationships.

Once you/your child have completed the interview, you will be provided with a post-study form by the research team, which provides further details about the research study and links to further support/resources for self-harm.

Will I be recorded and how will the recording be used?

The interviews will be recorded on secure, encrypted audio recorders and transferred onto a secure UCL server and password protected before analysis. The audio file(s) will then be deleted from the recorder.

The recordings will be transcribed (written up) by the research team UCL. We will do our best to ensure that no one will be able to tell you/your child took part in the study, as all personally identifiable information (e.g., names, locations) will be removed from the transcripts, which is called pseudonymisation. We will carefully keep the pseudonymised transcripts and audio recordings on a secure UCL server and may use anonymised quotations from the interviews for training, teaching, research, and publication purposes.

The audio recordings will be deleted from the secure UCL server at the end of the research study. However, the pseudonymised interview transcripts will be archived for 10 years.

What are the possible disadvantages and risks of taking part?

We do not believe that there are any risks to taking part in the interview, but we recognise that this is a sensitive topic. As such, we understand that it may be difficult or upsetting for you/your child to talk about their experiences self-harm.

If you feel upset during the interview, you do not have to answer any question and can take a break or stop the interview at any time. If you seem significantly distressed, the researcher will end the interview, so that we work with you and offer advice on how to seek further support. Furthermore, you will be provided with a post-study form by the research team, which provides further details about the research study and links to further support/resources for self-harm.

What are the possible benefits of taking part?

It is possible that you will enjoy talking with a researcher about your experiences. You may also take some satisfaction from giving time to a research project that could, eventually, lead to better mental health and wellbeing for young autistic people.

We will give a £20 Amazon or Love2Shop voucher to those who complete an interview, to thank them for taking part in the research study.

Who should I contact if something goes wrong?

If you are unhappy or dissatisfied about any aspects of your involvement in the research study, we encourage you to contact us so that we can try to resolve your concerns and find a solution. If you wish to make a formal complaint, please contact the Principal Research, Professor Will Mandy. However, if you feel that your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk with the ethics committee approval number for the study included in your email.

Will taking part in this research study be kept confidential? And are there any limits to confidentiality?

The information that we collect from you will be strictly confidential. However, if during the interview we discover that you are at immediate risk of harming yourself or others, or at risk from others, we are obliged to contact relevant people/authorities.

Before the interview we will routinely ask everyone for the contact details of a parent/carer and general practitioner (GP) to ensure that we can manage these situations appropriately. If we identify that you or someone else is at risk of being harmed, we will need to share this information with your parent/carer or GP and may need share this information with responsible authorities. If we took your parent/carer and GP contact details but they are not needed, we will delete them after the interview.

What will happen to the results of the research project?

We will write a research report so we can share the new discoveries we made with autistic people, clinicians, researchers, and other people interested in improving the lives of autistic people. If you would like a copy of this report, just contact the researchers and we will send it to you. We will also write an easy-to-read summary of this report that we can send to you if you would like it. Whenever we share findings from the project, we will make sure that you cannot be identified as a participant.

Local Data Protection Privacy Notice

The Data Protection Privacy Notice outlined below describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us by individuals and third parties. Your personal data will be processed if it is required for the research project. We will anonymise or pseudonymise and minimise the processing of personal data, wherever possible. The lawful basis that will be used to process your personal data are: 'Public task' for personal data. The lawful basis used to process special category personal data will be for research purposes.

Pseudonymised data containing non-identifiable information will be analysed by the research team. Audio recordings will be transferred at the earliest opportunity to a secure UCL server, then deleted from the encrypted audio recorder. The research team will write up (transcribed) and remove any personally identifiable information (e.g., names, locations), which is called pseudonymisation. The interview transcripts will be password protected and stored on a secure UCL. All study data will be stored electronically on password protected laptops/computers and a secure UCL server. You can withdraw your data from the research study up to 6-months after the interview data has been collected, before the data has been analysed and published. If you would like to remove your data from the research study, please contact the research team using the details provided.

All data will be handled according to the Data Protection Act 2018 and will be kept confidential. Contact details will be destroyed at the end of the research study, unless you indicate that you would like to be contacted about future research opportunities in the data sharing form.

The data controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk. Further information on how UCL uses your information can be found in our 'general' privacy notice: General privacy notice (<https://www.ucl.ac.uk/legal-services/privacy/general-privacy-notice>) and the privacy notice for research participants for health care purposes: Research participants for health and care purposes privacy notice (<https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice>).

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

Who is funding the research?

This research is funded by the Wellcome Trust.

Further support:

If you would like further support in relation to self-harm:

<https://www.youngminds.org.uk/young-person/my-feelings/self-harm/>

<https://www.mind.org.uk/information-support/helplines/>

<https://www.samaritans.org/how-we-can-help/if-youre-having-difficult-time/if-you-want-self-harm/>

<https://giveusashout.org/get-help/issues/help-self-harm/>

How do I take part?

If you read the information sheet and considering taking part in this research study. If you would like to take part or have any questions (now or in the future) about the research study, please contact us using the contact details below:

Researcher:

Lead Researcher:

Name: Erin Dawe-Lane
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Name: Professor William Mandy
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