

## Participant Information Sheet - Detailed

### Fictional Representations of self-harm PhD Project

**Researcher name: Veronica Heney**



#### Invitation and brief summary:

You are being invited to participate in a research project on fictional representations of self-harm. Self-harm is not frequently represented in books, TV, and films. It is possible that this may impact the way people talk about self-harm and how people seek help or support. The project aims to explore what representations are currently available to individuals who self-harm. It will also examine how individuals who self-harm feel these representations impact the way they understand their own experiences and the way they discuss them with others. The project will consist of an interview study and subsequent analysis by the researcher of fictional texts. The selection of these texts will be guided by the interviews, and will likely include books, television shows, films, comics, and other fictional media.

Please take time to consider the information on this sheet and to discuss it with family or friends if you wish, or to ask the researcher questions.

This information sheet will offer further details about:

- [How the interviews will contribute to the project, and what the discussion might cover](#)
- [The practicalities of the interview, including where it will take place and what might happen after the interview](#)
- [Benefits and disadvantages; this is a chance to contribute to hopefully useful research, however it may at times be distressing or difficult](#)
- [Anonymity; you can choose to be anonymised in any writing which discusses the project, or to be named, or to select your own pseudonym](#)
- [Payment for your time; you will be compensated for participation in the project either in the form of cash or a voucher as you prefer](#)
- [Leaving the project, and withdrawing your data](#)
- [Keeping your data confidential; all data will be stored securely and backed up](#)

#### Purpose of the research:

This project takes as its starting point the possibility that fictional representations in some way may impact the conversations that it is possible to have around self-harm. It works from the belief that the way we talk about self-harm matters, because such conversations can influence, positively or negatively, the experience and lives of people who self-harm.

Despite efforts to reduce stigma around self-harm, people who self-harm rarely seek help or support. Research into young people who self-harm suggests that they are more likely to initially approach informal contacts rather than to disclose to a medical practitioner. Talking about self-harming to friends, parents, teachers, colleagues, or partners can be an important step in the process of accessing support or help. But it is possible that this could be made more difficult by the lack of available representations of self-harm.

The project aims to examine existing fictional representations of self-harm and to explore how these might or might not impact disclosure and help-seeking, and if so in what ways. The results from the project will form the basis for a PhD thesis, and also for papers, presentations, and other work on the topic of representations of self-harm. This work may contribute to public policy and advocacy in a number of areas.

It is likely that between 20 and 30 people will be interviewed. The interview will probably involve discussion of:

- What fictional representations you are aware of or have consumed
- Whether they were important to you and if so in what ways
- Whether you enjoyed them or not
- Whether they had any impact on your experiences or understandings of self-harm
- How you think existing fictional representations might be improved

This project was originally designed as a result of the primary researcher's own experiences of self-harm, and the design has been further refined in consultation with an advisory group made up of individuals with experience of self-harm.

### **Why have I been approached?**

You have been approached because of your response to an advert for research participants with experience of self-harm, which may have distributed on a facebook page, on twitter, by a mailing list or other network, on an e-bulletin, on a webpage, through personal contacts or by relevant charities, or on the University of Exeter campus.

For the purposes of this research self-harm is defined as "an act, normally a repeated, habitual act, which in some way causes direct harm to the body but one where the focus and purpose of the act is this harm itself and not some other goal."<sup>1</sup> This definition therefore includes a wide range of practices, but is not intended to include attempted suicide (although we know that the categories overlap, and such experiences would not exclude you from taking part in this study).

It is entirely your decision whether you feel your experiences fit within this description. You will not be asked to define or describe the specific practices of self-harm which you have experienced, nor will you in any way be asked to authenticate or 'prove' your experience.

### **What does taking part involve?**

Taking part in the research involves participating in an interview on the topic of fictional representations of self-harm. The interview will be conducted by the primary researcher, whose own experiences of self-harm provided the original idea for the research. The interview will probably last between 1-2 hours. The interview would take place in a location of your choosing, such as in a café, a library, an office, or in your home; if you would like the researcher to arrange a space or a room for the interview then this will be arranged. As far as possible the researcher will travel to you, to ensure that you are not inconvenienced.

If you prefer not to be interviewed in person, then it will be possible to conduct the interview via skype or via the telephone. If you find verbal communication difficult then you may request to submit written responses, to ensure that your perspectives can still be included in the research.

The interview will be audio-recorded, and later transcribed, after which the audio file will be deleted. This transcript will be used to answer the research questions outlined above. It will be

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<sup>1</sup> Page 9, Steggals P. (2015) Making Sense of Self-harm: The Cultural Meaning and Social Context of Nonsuicidal Self-injury. 2015 New York; Palgrave Macmillan

used alongside the transcripts of other interviews and the researcher's own interpretation of various fictional representations of self-harm. Along with the interview participants will also complete a short (optional) form regarding demographic characteristics (race, gender, sexuality, disability, and age) which will be used to contextualise interview data.

### **What will happen after the interview?**

Participants will be offered the choice to request a copy of the transcript of their interview for approval, and they can amend this transcript or request sections are deleted. You will be offered the choice to be contacted for a follow-up interview if this might be useful. If you would prefer not to be contacted later then this will not in any way affect your participation in the first interview.

You will also have the choice to participate in and contribute to the analysis of your interview. This means that you can discuss with the researcher what you think your responses might mean, in the context of other interviews and the researcher's own interpretation of various representations of self-harm. While publications and the PhD thesis will inevitably be driven by the researcher's interpretation, this process will allow you to decide if you're comfortable with the direction that analysis is progressing in, and to contribute additional insight if you want to. This time will also be compensated (see below).

You will also have the choice to participate in follow-up activities, such as focus groups that explore the results of the project and what actions or interventions might be recommended based on those results.

### **What are the possible benefits of taking part?**

For yourself in particular, you might find it interesting to discuss fictional representations of self-harm. You might also find it meaningful to contribute to the research which might benefit others experiencing self-harm in the future. However, the potential benefits of the research are uncertain and far from guaranteed.

### **What are the possible disadvantages and risks of taking part?**

The main possible disadvantage is that discussions of self-harm can be difficult or even triggering. This can't be completely avoided, but the researcher will work hard to conduct these discussions sensitively and with care, and to always signpost any possible sources of support.

No one will be questioned about their particular experiences, and every effort will be made to avoid questions that might be upsetting; you won't be asked to back up your opinions on the representations with descriptions of experiences of self-harm. If you give permission, the researcher will check in with you after the interview, to make sure you're able to access the support you need.

### **How will I be supported during the interview?**

During the interview it will be emphasised that you can stop the interview at any time, that you can request to skip any question that you would prefer not to answer for any reason, and that you can request to take a break at any point in time. None of these choices will impact your participation in the study. You will also be provided with traffic-light cards (red, amber, green) that you can use to request to pause or stop the interview, if you feel it would be easier to do this non-verbally; you can choose to use the cards to signal other meanings if you prefer. If you have an object that is comforting to you in distressing situations, such as a fidget spinner, then please feel free to bring it.

You will also be asked if you would like to provide a phone number for a preferred contact. If the researcher feels you might have been distressed by the interview and might need some support she will ask whether you would like her to get in touch with this person. You will also be asked to provide the details for a GP or GP practice; the researcher will use these details to contact your GP only if she feels that your life might be in danger in the near future. If the researcher feels that there is imminent danger to your life or limb then she will contact a Crisis Management team or the Emergency Services. If you have any questions about the exact circumstances in which such a call would be made you can ask the researcher to discuss this in detail with you.

If knowing in advance the broad questions that might be asked would make taking part in the project easier, then you can request a copy of the interview topic guide prior to the interview. Your health and wellbeing is what's most important, and we're keen to take any steps to support that.

### **What will happen if I don't want to carry on with the study?**

You can leave the interview at any time without giving a reason. You can request that your interview recording and transcript be deleted. This request can be made at any time, although data will not be able to be erased from outputs (such as the PhD thesis, articles, presentations) that have already been completed, submitted, or are close to deadlines. Your data won't be used in future outputs once you have withdrawn.

### **Will I be anonymous, and what will happen to my contact details?**

If you choose, your involvement in the project will be completely anonymous; however if you prefer to be named this will also be possible, or you can elect to be referred to by a pseudonym of your choice.

If you choose, your contact details will be deleted immediately after the interview. However, in some cases you may prefer for your contact details to be retained:

- If you decide that you are happy for the researcher to contact you in the week following the interview to check in on your wellbeing
- If you would be open to a follow-up interview
- If you would like a copy of the transcript of your interview,
- If you would like to participate in interpreting the data,
- If you would like to participate in follow-up activities

If you select any of the options above your contact details will be kept securely until the relevant participation has been completed, for a period of up to seven years after the interview.

Your contact details will initially be securely held on an encrypted laptop, and will be transferred as soon as possible to a secure password-protected university server. Your contact details will be deleted at any time if you request that they are. Only the primary researcher (Veronica Heney) will have access to your contact details. To protect your anonymity while still allowing for the withdrawal of data, an anonymization key will be kept in a password protected document, separate to your transcript. This document will be stored on a secure university drive. Only the primary researcher (Veronica Heney) will have access to the anonymization key.

### **How will my information and transcript be kept confidential?**

All contact information will be kept securely on a secure password-protected university server for no longer than seven years. Consent forms will be scanned and stored on a secure university drive, and hard copies will be shredded Audio recordings will be stored on an encrypted laptop

and then will be deleted once they have been transcribed. Transcripts will be anonymised and stored, along with associated anonymised demographic data, initially on an encrypted laptop. The laptop will be stored in a locked university office, or will be in possession of the researcher. They will be transferred as soon as possible to a secure password-protected university server for the duration of the research project. Transcripts and demographic data will be retained for up to fifteen years following the completion of the PhD, to allow for articles and books to be written up over that period of time.

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing [dataprotection@exeter.ac.uk](mailto:dataprotection@exeter.ac.uk) or at [www.exeter.ac.uk/dataprotection](http://www.exeter.ac.uk/dataprotection)

### **Who will access my interview transcript and will it be archived?**

Following completion of the PhD interview transcripts will be archived in the UK Data Archive, as a result of funding requirements. However, you can choose for your transcript not to be archived and publicly available. Demographic data will not be archived. Archived transcripts can also be labelled for future re-use by other researchers in relevant projects. However you can also choose for your transcript not to be made available for re-use.

The supervisors [Prof Laura Salisbury; Prof Manuela Barreto] of the PhD project will have access to the transcripts in order to maximise the potential for effective supervision, and members of the project's advisory group will also read transcripts as a part of their contribution to analysis. If you choose, your transcript may also be shared with other participants who choose to participate in analysis, but this is entirely voluntary. If you choose to remain anonymous your identity will not be shared beyond the primary researcher. The transcripts will be backed up using OneDrive.

### **Will I receive any payment for taking part?**

All participants will be compensated for their time, as a reflection of your expertise and your vital role as co-creators of research knowledge. As an indication of the equal value placed upon the time of all contributors in the research process, you will be compensated in line with the primary researcher's most recent paid employment (as a Research Assistant). Therefore, all participants will be offered compensation for their time at the rate of £15.25 per hour. Payment will be made in cash or in the form of a voucher; you can choose whichever form is more convenient, and this preference can be changed at any time.

You will also be compensated for all expenses incurred by participating in this study: this includes travel expenses (which can be booked for you in advance, rather than claimed back subsequently), childcare expenses, and the expenses for an accompanying adult if this would be helpful for travel purposes.

### **What will happen to the results of this study?**

The results of this study will, in the first instance, be analysed alongside relevant fictional texts and used in the writing of the primary researcher's PhD thesis. The PhD thesis may form the basis for other publications and activities including books, journal articles, presentations, blogs, teaching, and outreach. If appropriate, the results of the study may also form the starting point for future research projects or for the development of interventions or actions.

### **Who is organising and funding this study?**

The project is primarily organised by Veronica Heney, a PhD student at the University of Exeter. The PhD is supervised by Prof Laura Salisbury and Prof Manuela Barreto, who will be involved in the project's design and implementation.

The project is funded by the Wellcome Trust, through the University of Exeter Wellcome Centre for Cultures and Environments of Health.

### **Concerns and care**

This project aims to be careful and caring towards people with experience of self-harm. If you have any feedback about how these aims might be better achieved please don't hesitate to contact Veronica Heney (details below). Furthermore, if you can think of any measures which might specifically help you to feel comfortable participating in the study, please don't hesitate to let us know.

This information sheet aimed to be comprehensive, but if you have any further questions we would be very pleased to answer them.

### **Who has reviewed this study?**

This project has been reviewed by the Ethics Committee of the Department of Psychology, College of Life and Environmental Sciences at the University of Exeter.

### **Further information and contact details**

If you would like to receive further information about this project or have any queries at all, please don't hesitate to contact Veronica Heney:

Wellcome Centre for Cultures and Environments of Health  
University of Exeter  
Queens Drive  
Exeter

[vh291@exeter.ac.uk](mailto:vh291@exeter.ac.uk)

If you are not happy with any aspect of the project and would like to complain, please contact the following individuals:

Nick Moberly, Chair of Psychology Ethics Committee  
Washington Singer Laboratories, University of Exeter, Perry Road, Prince of Wales Road,  
Exeter, EX4 4QG, UK  
[N.J.Moberly@exeter.ac.uk](mailto:N.J.Moberly@exeter.ac.uk)

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Thank you for your interest in this project