**INFORMATION SHEET FOR PARTICIPANTS**

*Ethical Clearance Reference Number: HR-18/19-11193*

**YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET**

**Critical social incidents in anorexia nervosa: Patients’ perspective**

**Version 2, 22/07/2019**

**Invitation**

We are inviting you to take part in some research. This sheet gives you the important information about the study, so that you know what is involved before deciding whether to take part. It is entirely up to you, and you should only take part if you want to. If you have any questions, please get in touch through the contact details at the bottom of the letter.

**What is the purpose of the study?**

Our research seeks to understand critical positive, surprising, and difficult social incidents in the life of someone with anorexia nervosa. We believe that asking people with lived experience of anorexia nervosa about important social situations or events that took place while they were acutely ill will help improve our understanding of the illness. Patients’ perspective of critical social situations or events could also help us shed new light on social-emotional difficulties that many theoretical models have argued play a crucial role in perpetuating anorexia nervosa.

**Why have I been invited to take part?**

You are reading this information sheet because you are a person with lived experience of anorexia nervosa, and we think you might be interested in taking part. Please read all the information about the study before deciding to take part, and please feel free to get in touch and ask us any questions you may have.

**What will happen if I take part?**

The study consists of completing an online survey. The online survey involves providing some demographic information about you as well as some information about your anorexia nervosa. You will also be asked to complete three validated questionnaires asking you about your eating disorder, your current quality of life, and your current mental state.

In the Critical Incident Questionnaire, you will be asked to think about some critical, significant incidents in your life that took place while you were acutely ill. By incident we mean any activity that involved you and other people who you are or were close to, including family members, friends, or other loved ones. Critical incidents are any incidents that had particular importance to you and that had a substantial impact – positive or negative – on the activity or on your day. We will then ask you to tell us about the critical incidents and answer some specific questions about them. We advise you not to choose critical incidents that would be too difficult for you to write about, answer questions about, or that would make you distressed, anxious, or very stressed.

**What to expect during the consent process?**

As the study is conducted online, you will be asked to complete an online consent form. Please think carefully when answering the consent form questions. Answering “Yes” to all required consent form questions and completing the online survey will be understood as you consenting to participate in the study and giving us permission to use your data in the analysis. If you answer “No” to any of the required consent form questions, please do not complete the rest of the survey or contact Jenni Leppanen (email: [jenni.leppanen@kcl.ac.uk](mailto:jenni.leppanen@kcl.ac.uk)) before continuing any further.

**What else do I need to know?**

* The online survey takes approximately 40 minutes to complete
* You will be given a username and password which you can use to access the online survey. This mean that you can take breaks, close the survey and come back to it whenever you want.
* We will keep information regarding your username, password, and any personal, identifying information (e.g. your name, email address) separate from your answers to the online survey.
* Only the study team will have access to your username, password, and any identifying information you wish to give us (e.g. your name, email address). This data will be kept confidential.
* We will keep your answers and data confidential. We will only notify someone else of your answers if we are concerned that you or someone else is at risk of harm.

**Do I have to take part?**

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. 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 complete an online consent form and you will be sent a copy of this consent form to keep.

**Incentives**

Once you have completed the online survey, you can choose to take part in a prize draw. The prize will be ten £10 Amazon gift vouchers.

**What are the possible risks of taking part?**

You will be asked to think about and recount some positive, surprising, and difficult critical incidents that occurred while you were acutely ill. Describing such events may induce psychological stress and anxiety. Therefore, we advise you not to disclose any critical events that you would find too difficult to write about, answer questions about, or that would make you distressed, anxious, or very stressed. You can also take breaks, close the online survey and come back to it when you want.

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

Your participation in this study will also help us improve our understanding of critical social incidents in anorexia nervosa. This, in turn, will enable us to build better tasks to assess these difficulties in experimental settings and potentially as part of treatment or clinical trials.

**How have patients and the public been involved in this study?**

Two people with lived experience of anorexia nervosa have been involved as consultants in this study. The consultants have supported the design and development of this study and will also oversee the analysis and interpretation of the findings.

**Data handling and confidentiality**

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). In order to take part in this study you will need to contact the study team to express interest via email. This means that the study team will have personal, identifying information about you (e.g. your name, email address). Only the study team will have access to your personal, identifying information, and this information will not be shared with anyone outside the study team. Additionally, if you choose to take part in the study you will be given username and password with which you can access the online survey. Only the study team will know your username and password and this information will not be shared with anyone outside the study team. Your personal, identifying information as well as your username and password will be stored separately from your answers to the online survey and will be kept secure in an encrypted file. We will not use your personal, identifying information or your username and password in data analysis or any reports or publications that stem from this study.

Your responses to the online questionnaire will be anonymised and stored securely with a participant ID number. Your username, password, and any personal, identifying information we have about you will be stored separately from the anonymised data. Only the study team will be able to link participant ID numbers to usernames, passwords, and personal, identifying information. Your responses to the online survey will be kept confidential. We will only notify someone else of your responses if we are concerned that you or someone else is at risk of harm.

All data collected from you will be kept confidential and stored in locked filing cabinets and on encrypted files. We will keep your data for 7 years and after the 7 years, we will destroy the data, in line with the Data Protection Act. During the 7 years, your data will be shared and analysed amongst the members of the study team. During this time, your data may also be used as part of other studies and shared anonymously with researchers outside of the study team, if you consent to this. Personal, identifying information or your username and password, will never be shared with anyone outside the study team.

**Data Protection Statement**

The data controller for this project will be King’s College London (KCL). The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a ‘task in the public interest’ You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the King’s College London Data Protection Officer Mr Albert Chan [info-compliance@kcl.ac.uk](file:///\\kclad.ds.kcl.ac.uk\anywhere\UserData\PSStore02\k1217397\My Documents\2018\info-compliance@kcl.ac.uk). If you wish to lodge a complaint with the Information Commissioner’s Office, please visit [www.ico.org.uk](http://www.ico.org.uk/).

**What if I change my mind about taking part?**

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you or your opportunities to take part in future research in any way. If you choose to withdraw from the study we will not retain the information you have given thus far.

**How is the project being funded?**

The study is funded by the Wellcome Trust (REF: 213578/Z/18/Z).

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

Findings will be published in peer-reviewed journals and scientific conferences. Only group level summary statistics and themes will be published and discussed in scientific journals and conferences, no personal identifying information will be published.

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact Jenni Leppanen (jenni.leppanen@kcl.ac.uk).

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

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: PNM Research Ethics Subcommittee (email: [**rec@kcl.ac.uk**](mailto:rec@kcl.ac.uk))

**Thank you for reading this information sheet and for considering taking part in this research.**