

INFORMATION SHEET FOR PARTICIPANTS:

Eating Disorder Service Provision for University Students

REC Reference Number: HR-17/18-6660

This research is being completed in conjunction with Student Minds, the student mental health charity. Student Minds has a long track record of supporting students with eating difficulties. The charity initially founded in 2009 to provide peer support for students with eating difficulties. For more information about Student Minds, please visit www.studentminds.org.uk

I would like to invite you to participate in this research project which forms part of a collaborative research project to understand eating disorder service provision. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

Lead researcher: Dr Nicola Byrom – Nicola.byrom@kcl.ac.uk

Dr Byrom is not a clinician and is unable to provide further support and advice around managing an eating disorder. If you are looking for information, support or advice, please visit: www.studentminds.org.uk/findsupport

What is the purpose of the study?

From our work in this area and previous research, we know that accessing professional support can be challenging. We know that students can find it difficult to receive continuous health care as move between home and university. We also know that good, early support is important.

There have been many calls for universities and GP services to provide and commission specialist support appropriate for the needs of university students. Student Minds, are launching an audit to establish to what extent appropriate services are available to support students with eating disorders.

This research project will form one component of that audit. In this study we are looking to consult with university students with experience of eating disorders across higher education institutions in the UK. The focus of the consultation is to establish:

1. To what extent do students with experience (current or previous) of eating disorders feel that they have received appropriate, sufficient and timely treatment and support;
2. Where students feel they have had good support, what this form of support was and how it was delivered;
3. What students would like to see in terms of support provision in the future.

Why have I been invited to take part?

We are inviting all current university students and recent university graduates (graduated within the last 3 years) who have current or previous experience of an eating disorder to take part in this study.

You do not need to have a formal medical diagnosis of an eating disorder – we are keen to hear from anyone who feels that they struggle with their eating.

You can only take part in this study if you are over the age of 18.

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 sign a consent form and you will be given a copy of this consent form to keep.

What will happen to me if I take part?

Because we want to hear from as many students as possible, we have designed a range of different ways for you to take part in this study. You may be able to take part in a 1-2-1 interview – these can take place face to face or via telephone. Alternatively, you may take part in the study by completing an online survey.

If you would like to take part in an interview, please check the Student Minds webpage for details on how to register your interest

<https://www.studentminds.org.uk/research.html#eatingdisorders>

You will be invited to leave your contact details and one of the researchers will contact you to discuss participating and arrange a date for the interview. We would encourage you to think carefully about participating. The interview will follow a semi-structured interview and we will discuss the following topics:

1. Are you aware of any support available specifically for young adults with eating disorders?
2. Have you considered accessing any of this support?
3. For any service you have sought support from;
 - a. What has been your experience of the **process** of accessing support?
 - b. What has been your experience of that service?
 - c. What were the positive aspects of this service?
 - d. How could the service have been improved?
4. Overall, do you feel you have received appropriate, sufficient and timely treatment and support? If not, where do you feel the gaps have been?
5. If we were designing a service just for you, what would this look like? Who would provide support? How would it be accessed?

In addition to discussing these topics, you will be asked to complete a short paper-based survey asking about how you would define your experience of your eating disorder, when your eating difficulties started and who you have turned to for support.

The online survey provides the option to answer these questions via a text based response if you would prefer.

In the sections below, we outline what will happen if you take part in a 1-2-1 interview or online survey. Please note, that you would only take part in one of these.

Taking part in an interview:

The interview will last for no more than 40 minutes. We will record the interview and transcribe this to support our research project. The interview can be completed face-to-face or via telephone.

What are the possible risks of taking part?

If you find talking about service provision distressing, you may prefer to complete the online survey instead or opt out of the research study all together.

Will my taking part be kept confidential?

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). The lead researcher (Dr Nicola Byrom) and two research assistants (current MSc students at KCL), working with the lead researcher, will be aware that you are taking part in the study. Your contact details, held to arrange an interview with you, will be stored on a secure online file at KCL. These contact details will be destroyed when you have completed your interview and checked the interview transcript with you.

One of the research assistants will contact you to confirm arrangements for you to attend the interview will conduct the interview with you. The interview will be recorded and transcribed. Through the interview we will not use your name, in this way we can partially anonymise the interview.

The interview will be transcribed by an independent transcription agency. They will have access to the interview recording but no additional information. Once the interview has been transcribed, the original audio recording will be destroyed and the transcription will be checked to further anonymise the record of the interview. The final, fully anonymised transcript, will be stored on a password-protected online SharePoint file at KCL, shared between the project research assistants and lead researcher. This will not be linked to your name or contact details. The transcript will be stored for 5 years following the data of the research before being destroyed.

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. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You are free to withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until the 1st of May 2020, after which withdrawal of your data will no longer be possible as we will have started to write the final report. If you choose to withdraw from the study we will not retain the information you have given thus far.

Completing an online survey

If you cannot join us for one of the 1-2-1 interviews or would prefer not to take part in an interview, you can still share your experiences with and thoughts on support services for eating disorders. You can do this through an online survey. The survey will contain free-text boxes to answer the topic questions listed above. In addition to these questions, there will be a few questions about how you would define your experience of your eating disorder, when your eating difficulties started and who you have turned to for support.

You can complete the online survey here: <https://tinyurl.com/EatingDisordersAudit>

What are the possible risks of taking part?

If you find thinking about service provision distressing, this study is likely to be distressing for you and we would suggest that you opt out of the research study.

Can I withdraw from the study?

Participation is completely voluntary, you are free to withdraw at any point during completion of the survey, without having to give a reason. Simply close the survey window in your web-browser. Withdrawing from the study will not affect you in any way. Once you have submitted the online survey you will not be able to withdraw your data from the study. This is because the online survey is set up to be fully anonymous.

Will my taking part be kept confidential?

This survey is anonymous. This means that nobody, including the researchers, will be aware of your identity, and that nobody will be able to connect you to the answers you provide, even indirectly. Your answers will nevertheless be treated confidentially and the information you provide will not allow you to be identified in any research outputs/publications. Your data will be held securely on a KCL online file, accessed by the lead researcher and research assistances. The data will be stored for five years following the research project.

The data controller for this project will be King's College London (KCL). Research is a task that the University carries out in the public interest. Your data will be processed in accordance with the standards set by the General Data Protection Regulation 2016 (GDPR).

What are the possible benefits of taking part?

Student Minds will use the data from this study to inform future service delivery within the charity. They will also use the data to support future campaign work within the charity to lobby government, universities and the NHS to address gaps in service provision. In taking part in this study you will be supporting this ongoing work to improve the provision of services for students with eating disorders.

What will happen to the results of the study?

We will retain and share data from this study in a fully anonymised form. This will help ensure that other researcher or service providers are able to consider your feedback relating to service provision directly. It will not be possible to identify you from the archived data.

We will produce a final report summarising the main findings. You are welcome to have a copy of this report – please let the researchers know that you would like a copy of the report. This report will inform future work at Student Minds around eating disorders. We further plan to disseminate research findings through academic publication and conferences within the UK.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the lead researcher for this study, Nicola Byrom using the following contact details:

Dr Nicola Byrom
Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience,
2.09 Addison House,
Guy's Campus, Kings College London,
SE1 1UL

Telephone: 02078 488 067

Email: nicola.byrom@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:

The Chair, Psychiatry, Nursing and Midwifery Research Ethics Subcommittee,
rec@kcl.ac.uk

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