



Participant Information Sheet

Project Title: Exploring the relationship between lived experience and treatment decisions for adults living with fecal incontinence

Hello, my name is Hannah Kimler and I am a PhD student in the School of Health in Social Science at the University of Edinburgh. My research is focused on gathering insight into the experiences of adults living with fecal incontinence and how those experiences impact a person's decision to access and/or adhere to fecal incontinence treatment. I understand that this can be a sensitive subject to discuss so please don't hesitate to contact me with any questions or concerns if you or someone you know are considering participating in the research!

You are invited to take part in this research project. Before you decide whether or not to participate, it is important that you understand the purpose of the research and what participation in the project will involve. Please take your time to carefully read and consider the following information. Please ask questions if anything is unclear or if you would like more information.

What is the purpose of the project?

The purpose of this project is to better understand the effects of your experiences as a person who is living with fecal incontinence on your decisions related to seeking and adhering to treatment for fecal incontinence.

Why have I been invited to participate?

You have been invited to participate in this study because you have self-identified as someone who meets the inclusion criteria for this study. In other words, you would describe yourself as someone who is over the age of 18, proficient in speaking/reading/writing English, a resident of Scotland, and living with fecal incontinence defined as the inability to defer defecation for more than five minutes.

Do I have to take part?

No. Participating in this project is entirely voluntary. It is your choice if you would like to take part in this study. If you decide that you would like to take part, you are still free to withdraw from the study at any time without giving a reason. Deciding not to take part or withdrawing from the study will not affect your medical care or legal rights.

Please note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses, and reports) prior to your withdrawal and so you are advised to contact the researcher at the earliest opportunity should you wish to withdraw from the study.



What does taking part involve?

If you choose to participate in this study, then please keep this Information Sheet. You will be asked to sign or complete an Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. You can complete this form in person or online

In a semi-structured interview, you will be asked to share what your experience of living with fecal incontinence has been like. You will be asked about times that you sought treatment and what your experience with that treatment was like. If you have never sought treatment for your fecal incontinence, you can still participate. This interview can take place in person at the University of Edinburgh, a place that is convenient for you, or via video call. You may be asked to participate in a brief follow-up interview which can be completed over the phone. Ideally, I would like to audio record your responses (and will require your consent for this). The primary interview will not have a time limit though interviews of this kind typically last anywhere from 45-90 minutes.

Are there any possible risks or disadvantages in taking part?

There are no serious risks or disadvantages to participating in this study. However, I understand that discussing your experiences as a person who has fecal incontinence may evoke some unpleasant emotions. You will have the opportunity to stop or take a break at any time.

If you experience any distress between now and the conclusion of the project, please tell a friend or family member. You may also wish to speak to your GP. Additionally, the NHS operates a 24/7 helpline which can be accessed in the following ways:

In Scotland, dial 111 or visit this website for more information:

<https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-support/mental-health-services-at-nhs-24>

In England, please follow the instructions on this website: <https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

What are the possible benefits of taking part?

There are no direct benefits, but by sharing your experiences with me, you will help me and the University to better understand how your experiences have shaped your treatment decisions. The data that I collect in this project may be used to improve health care providers' understanding of what it is like to live with fecal incontinence and how that may affect treatment options and outcomes for people who have it.



Will I be reimbursed for any expenses or for my time?

Unfortunately, I am not able to offer any reimbursements at this time.

How will we use information about you?

We will need to use information from you for this research project. This information will include:

- Your name
- Your contact details
- Your age
- Your gender

People will use this information to do the research or to check your records to make sure that the research is being done properly. All of your data will be processed and stored in accordance with the General Data Protection Regulation (GDPR) along with the Data Protection Act 2018 (DPA). The project will be also be guided by and adhere to the University of Edinburgh's data protection guidance and regulations which you can view here:

<http://www.recordsmanagement.ed.ac.uk/InfoStaff/DPstaff/DataProtectionGuidance.htm>

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed. Your data will only be viewed by the researcher. All electronic data will be stored on a password-protected computer file and all paper records will be stored in a locked filing cabinet. Your consent information will be kept separately from your responses in order to minimise risk.

Once we have finished the study, we will keep some of the data so we can check results. I will write my reports in a way that no one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information at <https://www.ed.ac.uk/records-management/privacy-notice-research>

- by asking the researcher



- by sending an email to h.kimler@ed.ac.uk

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you until the research project and all associated publications are completed and your anonymised data for a minimum of 3 years.

What should I do if I want to take part?

If you would like to take part, or are interested in learning more, please send me an email at h.kimler@ed.ac.uk by September 31st, 2023, with the subject line “Participant”. I will respond to you via email within one week.

What will happen with the results of the research project?

The results of this study will be used for my PhD dissertation, which will be publicly accessible online through the University of Edinburgh repository. I may also use the data from this project to write research articles which may be published. You will not be identifiable from any published results. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name. With your consent, your anonymised information may also be kept for future research. I am also happy to send a more concise summary of the project findings to all participants. This summary will be sent to participants by email.

Who is organizing and funding this research?

This study has been organised by Hannah Kimler, PhD student in the School of Health in Social Science at the University of Edinburgh and is sponsored by the University of Edinburgh. I am the sole researcher involved in this project.

Who has reviewed this project?

This research project has been reviewed by the School of Health in Social Science Ethics committee at the University of Edinburgh.

COVID-19 Protocol

Please note that if you choose to participate in this study, you are expected to contact the researcher prior to meeting in person if you have experienced any COVID-19 related symptoms, or have been in contact with a COVID-19 positive individual in the 14 days prior to your scheduled interview. You are not required to meet in person and, if you wish, the interview can be done via video call.



Who can I contact?

If you have any further questions about the study, please contact the lead researcher, Hannah Kimler at h.kimler@ed.ac.uk.

If you would like to discuss this study with someone independent of the study, please contact Mr Seamus Prior at Seamus.Prior@ed.ac.uk.

If you wish to make a complaint about the study, please contact Professor Matthias Schwannauer, the Head of School of Health and Social Science via email: headofschool.health@ed.ac.uk or via post: Professor Matthias Schwannauer, School of Health and Social Science, University of Edinburgh, Teviot Place, Edinburgh, Scotland EH8 9AG

Or the Research Governance Team (cahss.res.ethics@ed.ac.uk)