

## Inflammatory Bowel Disease and depression and/or anxiety: patient's perspectives

### Participant Information Sheet

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the research study is about and what your participation would involve, to enable you to make an informed choice about whether or not you would like to participate in this study entitled “Inflammatory Bowel Disease and depression and/or anxiety: patient’s perspectives”.

The purpose of this study is to explore young adult’s perceptions of the relationship between Inflammatory Bowel Disease and depression/anxiety, and how information about that relationship is communicated to young adults. Should you choose to participate, you will be randomly sorted to one of two groups. Members of each group will be asked to attend a focus group which will consist of approximately 6-8 participants, and will last between 60-90 minutes. Participants in each of the focus groups will be asked to reflect on and discuss topics related to Inflammatory Bowel Disease and depression/anxiety, and the way in which information is presented about the relationship between these. This study will not provide intervention for mental health difficulties or information about Inflammatory Bowel Disease. The demographic information that you provide (i.e., gender, age, age at diagnosis) will be combined with other data in order to describe the overall sample of participants, and will not be identifiable at an individual level.

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so, you can refuse to participate in the group discussion, or decide to withdraw from the study at any stage up to two weeks after completion of the study.

Every effort will be made by the research team to protect your confidentiality and anonymity throughout the study. Due to the nature of a focus group however, it is not possible to guarantee confidentiality. We would ask all participants to respect that the focus group is a space whereby

all contributions are shared in confidence, and confidentiality is encouraged out of respect to other participants. Confidentiality is a core value of the researchers, and we hope that participants will also appreciate the importance of this. It will be necessary to record the audio content of the focus groups using an audio recording device in order to collect data. The content of this recording will then be transcribed into text, and pseudonyms (fictitious names) will be used in order to protect the confidentiality of participants.

The anonymous data will be stored on a secure University College Cork supported online storage platform. The data will be stored for minimum of ten years.

The information you provide may contribute to research publications and/or conference presentations. The information that you provide will also contribute to a thesis.

We do not anticipate any negative outcomes from participating in this study. We do not intend to cause any distress to participants. Some of the topics broached in the focus group, however, are of a sensitive nature. Should you wish to do so, you can choose to refrain from discussion of any topic during the group, or to withdraw from the study.

Should you require further support, we recommend that you speak to your GP regarding the support services in your local area.

Should you experience concerns arising from participating in the research, the details for support services provided below may be of assistance:

**SpunOut Text About it:** Free 24/7: Text 50808 or 086 1800 280 (48 or An Post Network Users), <https://www.textaboutit.ie/>

**Crohn's and Colitis Ireland:** <https://crohnscolitis.ie/>

**Tame Your Gut:** <https://www.tameyourgut.com/>

**HSE Website:** <https://www2.hse.ie/conditions/crohns-disease/>



This study has obtained ethical approval from the UCC Clinical Psychology Research Ethics Committee (CPREC).

If you have any queries about this research, you can contact me at [121102737@umail.ucc.ie](mailto:121102737@umail.ucc.ie) or the research supervisors, Dr Samantha Dockray at [s.dockray@ucc.ie](mailto:s.dockray@ucc.ie) and Dr Kim Keating at [KKeating@ucc.ie](mailto:KKeating@ucc.ie).

If you agree to take part in this study, please complete the consent form overleaf.

## Research Consent Form

I.....agree to participate in Chloe Feeley’s research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the study, in which case the material that contains anything that I said during the focus group will be deleted. Other participants responses to things I said during the focus group will be retained unless it includes material shared by me. I understand that due to the group nature of the study, if the voices of participants are similar and/or overlapping it may not be possible to identify and delete all of the data that I have contributed. The researchers will make every effort to identify and delete any contribution you have made.

I agree to keep all information discussed by other participants during the focus group confidential, and I understand that confidentiality cannot be guaranteed when attending a focus group due to the nature of group discussion.

I understand that anonymity will be ensured in the write-up by disguising my identity. The researchers will use their discretion to redact or disguise any information at transcription stage which could be potentially identifiable, this also includes the names of General Practitioners, Consultants, hospitals, clinics and local services (for example, where a participant mentions “Cork University Hospital”, this will be replaced by “a hospital in the Munster region”).

I understand that disguised extracts (e.g. my name / location / services won't be used) may be quoted in presentations and publications (e.g. article, book chapter, student thesis, social media publicity of the study's findings, etc.) if I give permission below (please tick one box):

I agree to participate in this study

I do not agree to participate in this study

Signed: .....

Date: .....

PRINT NAME: .....