

ADVISORY GROUP INFORMATION SHEET

Chronic fatigue is not just feeling tired

it's an overwhelming sense of continuing tiredness, lack of energy, or feeling of exhaustion

it is not relieved by rest or sleep

We are setting up a **paid advisory group** to help develop our research about understanding **fatigue** in young people living with **inflammatory bowel disease (IBD)**.

We are inviting people aged **16-25** with a diagnosis of IBD who experience fatigue to join our advisory group because we would like our research to be relevant to people currently living with IBD.



This research is being conducted by Suzy MacDonagh as part of a PhD in Health Psychology at the University of Gloucestershire and funded by Crohn's & Colitis UK.

We want to hear about your thoughts and ideas to help shape the research!

WHAT IS AN ADVISORY GROUP?

An advisory group is where people from different backgrounds work together to make research relevant and accessible. We care about your experiences living with IBD and we want to know how you would carry out this study.

Our research will explore the everyday experiences of young people living with fatigue and IBD. Improving understanding of what it is like to live with fatigue will help us to find out how best to

support young people, their families, and healthcare professionals to recognise the challenges of fatigue and explore ways to help manage it.



it takes
guts

It is important that research like this is designed with members of the community that is being researched to ensure it reflects your experiences.

On the advisory group you will be adding to the development and outcomes of a research project as a partner, but you will be unable to take part in the study as you will have contributed to its design. If you would rather be a participant instead, please let us know at picturingIBDfatigue@glos.ac.uk and we will let you know when the study starts.

WHAT WILL THE GROUP DO?

There will be a one-hour meeting every three months from October 2023 until the end of the project, which will be about 2 years and 8 meetings in total. The group will meet online using Microsoft Teams and any materials to be discussed in the meetings will be supplied at least 2 days before the meetings. We will also send regular updates on the project by email.

We need your support to help people living with Crohn's and Colitis

During each meeting we will discuss parts of the project such as:

- Wording of questionnaires and instructions - *what to ask and why?*
- Design of study advertising - *would you see the ad and want to take part?*
- Inclusivity of study materials - *would everyone feel able to take part in this study?*
- Accessibility of websites used in the study - *are they quick and easy to use?*
- How to make sense of the results of the study - *what does it mean to you?*
- Development of supportive resources - *how can we help?*

Optional - In addition to being a part of the group, there may also be an opportunity to help with an exhibition of photos taken as part of the study.

Confidentiality - Any information shared in the group will be confidential and you do not need to share anything personal. Contact details (name and address etc.) will be stored securely according to General Data Protection Regulation (GDPR) and will **not** be shared outside of the research team.



Payment - You will get a £5 Amazon voucher for every meeting, including if you are unable to attend due to illness but are able to later send comments. You will get a certificate of participation at the end of the study which can support UCAS and job applications.



HOW CAN I JOIN IN?

If you are aged 16-25 with IBD and can attend online meetings in a confidential space, then please scan the QR code or use the link below to fill in a form with your name, age and contact details and we will get back to you as soon as possible.

By entering your details, you are not committing to take part, but we will get in touch with you with more information.

You can change your mind at any time.



<https://glos.onlinesurveys.ac.uk/picturing-ibd-fatigue-advisory-group>

If you have any questions, please email: picturingIBDfatigue@glos.ac.uk

Thank you!

**CROHN'S &
COLITIS UK**

FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER