

## **INFORMATION SHEET FOR PARTICIPANTS**

*Ethical Clearance Reference Number: LRS-19/20-18288*



**TITLE:** The role of psychological flexibility on internalised stigma and patient outcomes in Inflammatory Bowel Disease (IBD).

### **RESEARCHERS:**

Mr Darren Reynolds (Trainee Clinical Psychologist)

Dr Trudie Chalder (Professor of Cognitive Behavioural Psychotherapy)

Dr Claire Henderson (Reader in Public Mental Health)

### **1. INVITATION**

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish.

### **2. WHAT IS THE PURPOSE OF THE STUDY?**

Some people with IBD are known to experience stigma related to their health condition. This stigma is sometimes internalised ('internalised stigma') by individuals, which can be distressing and disruptive to their lives. The aim of this current research is to develop knowledge of the psychological processes that are involved in the process of stigma being internalised, as well as the effect of internalised stigma on patient outcomes for those diagnosed with IBD. This research forms part of a student's Doctorate in Clinical Psychology (DClinPsy) thesis.

### **3. WHY HAVE I BEEN INVITED?**

We invite anyone aged 18 and older, who has a diagnosis of IBD, to participate and complete some questionnaires which will take around 30 minutes in total. The study contains various questions which ask you about yourself and your experience of living with IBD. This study has received ethical approval. This means that a panel of people external to the research team have reviewed and approved the study as being ethical.

### **4. WHAT WILL HAPPEN TO ME IF I TAKE PART?**

If you would like to participate, you will be asked to complete some questionnaires electronically on 'Survey Monkey'. By clicking the link below you will be directed to the questionnaire. This link is compatible with most internet browser settings.

### **5. WHAT DO I HAVE TO DO?**

The questionnaire will ask you questions about yourself, how you manage difficult thoughts and feelings, and your experience of living with IBD.

### **6. DO I HAVE TO TAKE PART?**

No. 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. If you choose to take part you will be asked to provide your consent. To do this you will be asked to indicate that you

have read and understand the information provided and that you consent to your anonymous questionnaire response data being used for the purposes explained.

You are free to withdraw at any point during completion of the survey, without having to give a reason. You can do this by simply closing your internet browser window. Withdrawing from the study will not affect you in any way. Once you submit the survey, it will not be possible to withdraw from the study because the data will be fully anonymous. Please do not include any personal identifiable information in your responses.

**7. WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?**

The findings from this study should help increase awareness within the profession about the psychological processes that may lead to internalised stigma within adults with IBD, consequently having a positive impact on clinical practice and improving patient care (e.g. developing new psychological interventions for targeting internalised stigma).

Participants will be given the option to enter themselves into a prize draw to win one of ten available £15 Amazon vouchers. Apart from this optional prize drawing, there are no immediate benefits from this research at an individual level.

**8. ARE THERE ANY DISADVANTAGES OR RISKS TO TAKING PART?**

This subject area is sensitive and has the potential to evoke emotional reactions in some participants, although we are not anticipating this to be of a significant or long-lasting nature. In the event that you do feel that you need some support with any emotional reaction or advice about the topic area being discussed, the research team have included a list of helpful support networks and links of services that you can access at the end of the questionnaire.

**9. WHAT HAPPENS WHEN THE RESEARCH STUDY STOPS?**

The questionnaire will thank you for your time and terminate the session. No follow up is being conducted at this time. Individual anonymous responses to the questionnaires will be collated and analysed by the research team.

**10. WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?**

This research 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 King's College London (KCL) computers.

**11. DATA PROTECTION**

The data controller for this project will be 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). If you would like more information about how your data will be processed in accordance with GDPR please contact the research team (see #17).

## **12. WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?**

The results of the study will be summarised in a thesis to be submitted to the Doctorate in Clinical Psychology (DClinPsy) course at King's College London by the lead researcher, Darren Reynolds. Results from the study may also be published in a peer-reviewed scientific journal. The anonymous data set will not be shared with any third parties or made publicly available.

## **13. WHO SHOULD I CONTACT FOR FURTHER INFORMATION?**

If you have any questions or require more information about this study, please contact lead researcher (see #15)

## **14. WHAT IF I HAVE A QUERY OR A CONCERN ABOUT THIS STUDY?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (see #15 for lead researcher contact). 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:

- Trudie Chalder (Professor of Cognitive Behavioural Psychotherapy)  
Email: [trudie.chalder@kcl.ac.uk](mailto:trudie.chalder@kcl.ac.uk)

## **15. CONTACT DETAILS OF LEAD RESEARCHER**

- Darren Reynolds (Trainee Clinical Psychologist)  
Email: [darren.reynolds@kcl.ac.uk](mailto:darren.reynolds@kcl.ac.uk)

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

**Please follow the link below to access the online study:**

**<https://www.surveymonkey.co.uk/r/YR6JNSG>**