**Patient information sheet**

**Exploring Social Media Preferences Among the Inflammatory Bowel Disease Population: A Pilot Study.**

**V2 /19.09.2019**

You are being invited to take part in a research study. Before you decide if you want to take part in the study or not, it is important to understand why the research is being done and what it will involve. Please read the following information and take your time to consider if this is right for you.

**What is the purpose of the study.**

The purpose of this study is to understand the social media preferences among people with inflammatory bowel disease. We know that with the explosion of internet and social media usage, many people with IBD will have access to a wide range of information about disease symptoms and management. However, while the internet and social media provides a wide range of information, we know that the information found on social media might not always be accurate or correct, due to not being regulated. A previous study in the USA has found that people with IBD have difficulties in accessing high quality information on social media. We would like to find if this is the case in UK as well. We would also like to find out what are the information preferences and needs for people with IBD in the UK, which will hopefully enable us to influence the provision of high quality information for those that do use social media for this purpose.

**Do I have to take part?**

No, your participation in this research project is voluntary.

**What does it involve?**

We are inviting to complete a survey and take part in a focus group (optional choice).

1. Survey

The Survey will consist of 58 questions to understand your preferences and usage of social media for health purposes.

The survey will take no longer than 15 minutes to complete. After you complete the survey, you would be asked to take part in a focus group. Participation in the focus group is not compulsory, however your input is greatly appreciated.

1. Focus group (optional choice)

If you agree to take part in the focus group, we may send you an email to invite you to participate. The focus groups will be held at University of Salford.

The focus group will enable us to generate in-depth understanding of Social Media preferences among IBD population.

Should you choose to take part in the focus group the discussion will be conducted by our research team, and should last 1-2 hours maximum and will take place at The University of Salford. The focus group discussions will be audio-recorded.

Basic anonymous demographic data will be collected (age, sex, ethnicity, level of education, disease type, disease severity, and duration of disease) will be asked (a sheet will be handed to you to complete before the focus group begins). We will reimburse your travel expenses on the day.

**What will happen to me if I take part?**

*Survey*

* This leaflet gives you the information as to what you will be expected to do if you decide to participate in the research. Once you have read the information there will be opportunity for you to contact the researchers to ask questions about the research
* If you are happy to participate please click the link below (at the end of this document) to complete the survey.
* At the end of the survey you would be asked to take part in a focus group. This is not compulsory, but if you do want to participate, we would require your email address and name so we can contact you with dates/times.

*Focus group*

We will contact you via email to provide further details (venue, date and time). Please note that we are only able to include 10 participants in the study and you might not be contacted.

During the focus group you will:

* Sign the consent form
* Complete a form with your demographic details (age, sex, ethnicity, level of education, disease type, disease severity, and duration of disease)
* Take part in discussions to share your personal experience of using social media for health purposes (1-2 hours)

**Any benefits to you?**

There will be no direct benefit to you for participating in this research but from the information you provide we will be better able to understand the social media preferences and usage, which will hopefully enable us to influence the provision of high quality information for those that do use social media for this purpose.

**Any risk to you?**

We do not expect there to be any disadvantages or risks to you during the study. However,if you decide to join the focus groupthe risk of being involved in a group discussion is that you may share information in front of other people that you later regret saying. Participants will however, will be asked to sign consent before the discussion to ensure that the issues discussed remain confidential after the meeting. Should you have concerns around being identified / protecting your anonymity and the confidentiality of the information you share within the context of this research through your participation in the survey/focus groups the consent you will be asked to sign also makes clear that anything you share will be treated as confidential information by the researchers your name (or chosen name) will not be used in any written reports or presentations.

**What will happen if I don’t carry on with the study?**

This is not a compulsory project. If you decide for any reason to withdraw from the study this would be possible for the focus group within the first two months of taking part. After that, your contributions will remain part of the study.

You can leave the focus group discussions at any time if you are no longer happy to be involved.

If you decide to withdraw from the focus group (within the two months period) please contact the Project Lead: Dr Mariyana Schoultz (m.schoultz@salford.ac.uk) and request that the information you provided will be removed from the study.

However it is important to understand thatafter two months withdrawal of your information will not be possible as the information from the focus group has been fully anonymised.

**What the researcher will do with the data**

The University of Salford is the sponsor for this study based in the United Kingdom. We will be using information from you (data) in order to undertake this study and will act as the data controller for this study.

The discussions that take place during the focus group will be audio-recorded so we can capture each person’s contribution to the discussion. The recording will be transcribed by (researchers and/or transcription contractor) and any identifying data removed (e.g. names, particular places and organisations). This will provide us with valuable information on social media affordances.

We are responsible for looking after your information and using it properly.

We will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from the University of Salford and regulatory organisations may look at your research records to check the accuracy of the research study.

The University of Salford will keep identifiable information about you until the study has finished. Then anonymised data will be stored for a period of 3 years after the study has finished.

The data will only be used for non-commercial, scholarly research and teaching. Your details will not be shared and will remain confidential. False names (pseudonyms) will be used and you will not be identifiable in any material that will be made available to the public through research publications.

You can find out more about how we use your information by contacting xxxx (Email: xxxx)

**Will my taking part in the study be kept confidential?**

The research data will remain confidential between you and the researchers. Any information stored which you provide will be anonymous and not identifiable to you.

We must highlight that if you do share anything that is illegal, or suggests risk to yourself or others, the researcher is duty bound to report it to the appropriate authorities.

**WHAT NEXT?**

* **If you are happy to take part in the research please click on the following link (SurveyMonkey link)**
* **If you choose to take part in the focus group, we will contact you via email**
* **If you are unsure, talk to someone you trust and feel they will be able to help you make a decision as to whether or not you should participate.**

**If you are not happy or you need extra support**

If you have any complaints regarding any aspect of how this research is being conducted then please contact Prof Ben Light: (Tel No: 01612950159 & Email: B.light@salford.ac.uk), Mary Seacole Building, Frederick Road Campus, Salford, M6 6PU. However, if you remain dissatisfied, please contact Dr Jo Cresswell, Associate Director Research, Research & Enterprise Division, Room 208, Joule House, University of Salford, Salford, M5 4WT. Tel: 0161 295 6355. E: j.e.cresswell@salford.ac.uk. If you need to discuss any issues arising from the focus group further, participants can access Mind in Salford on 01612124880 or Cronh’s and Colitis UK on 0300 222 5700.

**Lead researcher’s name:**

**xxxxxx E-mail:** **xxxxxxx**

**xxxxxxx Email xxxx**

**Thank you for taking time to read this leaflet**