# The MUSIC IBD Study: A strategic vision to combine high quality clinical care with research

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**Gut Research Unit - Mission statement:**
‘Our mission at the Gut Research Unit is to better understand how the gut works in both health and disease. Research is our passion and your care and experience as a patient is our top priority. Together we will find new and more effective treatments for IBD’.

## Background:

The MUSIC IBD study is focused on understanding why gut inflammation develops in Crohn’s disease and Colitis and how it heals (or not) in response to medical treatment. Our study will provide important data into potential new treatments or tests that can accurately track the progress of IBD.

## Who is involved?

1. The patient participant
2. The MUSIC PPI team
3. The MUSIC Clinical and Scientific Research team
4. Your NHS clinical team
5. National patient charitable groups (such as Crohn’s Colitis UK, Cure Crohn’s Colitis and GUTS UK)
6. Our funders, Helmsley Charitable Trust
7. University of Edinburgh Patient and Public Involvement team

## Why is patient engagement and involvement important?

Our study has been designed with a lot of direct input from our own patients. Following the initial stages of our study, we increasingly recognized that:

1. Being diagnosed with or experiencing a flare of Crohn’s or colitis is a difficult, stressful, and challenging time.

2. Getting the right treatment and restoring your quality of life by achieving remission in a timely manner is our top priority.

3. Providing care, tests, and treatment decisions during your flare requires a lot of input from your clinical team – and we don’t always get it right the first time!

4. Participating in research can be daunting, inconvenient, and/or be viewed as a hindrance to your usual NHS clinical care.

5. Throughout our PPI members’ experience with IBD, we have realised that more information being available could improve the understanding of how IBD can impact lives.

However,

1. Working together, it is possible to conduct good research whilst maintaining a very high quality of clinical care

2. By putting patients at the heart of our work, your involvement can drive not only the development of effective communication but the key direction this research takes.

3. This is a fresh opportunity to find a new approach that can significantly improve and change the current status quo of IBD clinical care and treatment.

**Aims of the research team:**

1. To develop a progressive, equitable, and responsive partnership with you (the patient participant) to improve clinical care and research

2. To improve the experience of patient participation in research; and present an opportunity to drive and maintain the overall high standards of clinical care

3. To ensure that we develop an approach that is sustainable and open for ongoing improvements as we learn; and that the new knowledge gained will be shared for the benefit of the wider community beyond our study.

4. To ensure that patients never feel alone or without help during their experience with IBD. We will make information and contacts available for anyone with questions regarding their clinical care.

**How will the research team ensure the aims are met?**

1. Broadly, the research team will work with the MUSIC PPI (Patient and Public Involvement) group to develop a 2-way iterative partnership where we learn from each other to improve the patient experience of research, clinical care and also our research.

2. Finding the right skillset and expertise from our MUSIC IBD team and patient participants to enhance our progress in a symbiotic manner

3. To find and nurture effective communication channels to engage the patient participants with the new scientific and research data of this study as it evolves and to show that your input has shaped our research in a positive manner

4. To ensure that proper and realistic investment is put into these activities and are translated into meaningful outcomes.

5. To work with experts in PPI to ensure that the new knowledge is captured so that we can share and pass the improvements to everyone else in the wider IBD field, across Scotland and UK.

6. We will also give the patient a voice, so that any concerns can he heard by the research and PPI teams. Feedback is crucial in determining how our study is progressing and what more we can do to fulfil our overall aims.

## What are the fundamental elements of the PPI strategy?

From the researchers' perspective, patient recruitment and retention are essential to the success of every study, and they too need to feel that their patients understand:

A. What questions they are trying to answer and that patients understand and are comfortable with what is being asked of them.

B. That the PPI & Engagement team seeks to build in opportunities for researchers and patients to come together and share their experiences, ask questions and where possible implement their suggestions.

The MUSIC PPI team has identified a number of opportunities to meet both the expectation of researchers and their patients. These opportunities include:

### 1. The Website:

The website (www.musicstudy.uk) will be the main portal for patients to find information relating to the study and will include:

- Audio and video introductions from the PPI and research team.
- Explanatory graphics describing the study.
- Downloadable Patient Information Sheets.
- Contact addresses.
- Signposting to other resources.
- Regular podcast sessions, explaining our own experience with IBD and covering a range of topics. These will be beneficial to the patient and encourage them to speak freely about their condition.

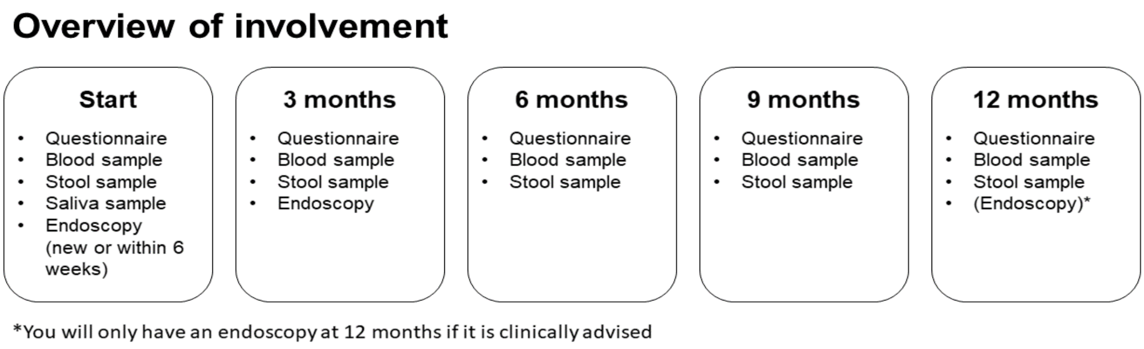
### 2. Newsletter:

A downloadable newsletter hosted on the website as a pdf. Ideas for content may include:

- An update from Gwo-Tzer (Chief Investigator) /Emma (Trial Manager).
- Recruitment figures to date.
- A patient story/experience.
- Sign post to relevant upcoming activities.
- Health advice bullet points.
- Links to IBD health advice: such as signposting to websites, MUSIC PPI podcasts, and information articles.

### 3. Patient Feedback:

It is important to spot any problems or opportunities to improve the patient experience as the study progresses.



**Overview of involvement**

| Start | 3 months | 6 months | 9 months | 12 months |
|---|---|---|---|---|
| • Questionnaire<br>• Blood sample<br>• Stool sample<br>• Saliva sample<br>• Endoscopy (new or within 6 weeks) | • Questionnaire<br>• Blood sample<br>• Stool sample<br>• Endoscopy | • Questionnaire<br>• Blood sample<br>• Stool sample | • Questionnaire<br>• Blood sample<br>• Stool sample | • Questionnaire<br>• Blood sample<br>• Stool sample<br>• (Endoscopy)* |

*You will only have an endoscopy at 12 months if it is clinically advised

To capture patients' experience throughout their participation in this research, the team will develop a short questionnaire to be administered at key points in the research journey. This will be available in the newsletter or to download from the website.

### 4. PPI and engagement evaluation:

Evaluation of the PPI group and strategy has been recognized as an important element of ongoing development.

- This could be conducted ad hoc, as a structured ongoing evaluation, or based on reflective feedback at certain intervals.

- An alternative option would be to recruit an interested postgraduate student to formalize the evaluation. Going down this formal route may generate more learning for the team and is likely to be appreciated by the current and any future grant making bodies.

## Concluding statement:

The goal is to ensure that patient participation in the IBD MUSIC study is realistic, informative, and worthwhile for all concerned.

Central to patient and public participation in the design and planning of research activities is the belief that being involved in research should be a learning opportunity for patients. With learning, comes understanding and when a patient understands their condition, it empowers them and brings about an increased sense of control and a more optimistic and positive mind set as they deal with the flare of their disease.

## References/Links :

https://www.publicengagement.ac.uk/nccpe-projects-and-services/professional-development/engage-academy.

https://www.publicengagement.ac.uk/sites/default/files/publication/what_works_engaging_the_public_through_social_media_november_2018.pdf

## Useful contacts :

Carol Porteous : PPI Involvement adviser. Welcome Trust Edinburgh.