

**PRO-FIT**

Participatory Research for Optimising FIT

Enhancing bowel cancer detection • Addressing health inequalities



Workshops

Participant Information Sheet

Thank you for your interest in our study.

Bowel cancer is a serious illness that causes many deaths each year in the UK. If it is found early, people have a much better chance of getting better. There's a poo test (Faecal Immunochemical Test or FIT) that can find bowel cancer early, but many people, especially those who have a harder time getting healthcare, don't use it. This means they find out they have cancer later, which makes it harder to treat. **We want to understand why some people don't return the test and find ways to improve this.**

We would like you to take part in a research project about this. Before you decide if you want to take part, please take time to read the following information carefully.

- You are being asked to share your ideas and experiences in a group workshop with other people.
- This will involve attending 5 in-person workshops lasting about two hours each. You will be offered a payment of £50 for your participation in each workshop. We will reimburse your travel expenses.
- Other people at the workshop will include community members, healthcare professionals, and researchers. We'll make sure to use everyday language throughout the workshop so everyone can join in, no matter what their background is.
- During the workshop, we will audio record discussions and take photographs. You do not have to be in any photos if you don't want to. We will treat all the information you share with us in confidence.
- If you would like to take part, you will be asked to complete a consent form. A consent form is a written record that you're happy to take part in the study.
- You do not have to take part and you can stop taking part at any time during the study without giving a reason.
- **If you are interested, please complete an expression of interest form. We will contact you to check if you would like to take part.**

The following pages explain the study in more detail and give you important information about taking part.

How to get in touch: For any questions or concerns, please contact Naseeb Ezaydi (Project Manager): n.ezaydi@sheffield.ac.uk

What is the purpose of the study?

Bowel cancer is a serious health issue in the UK:

- 44,000 new cases each year
- 16,800 deaths each year
- When found early, 95% of people survive at least 5 years
- When found late, only 10% survive 5 years
- Currently, only 48% of bowel cancers are found early (NHS target is 75%)

The Faecal Immunochemical Test (FIT) is a test that can be done at home. It can help find bowel cancer early. However, about 30 out of 100 test kits are never returned. This means around 2.1 million people each year miss the chance for early cancer detection.

We don't know why so many people don't return their tests. It is important to understand why this happens and how we can help.

Why have I been invited?

You are being asked to take part in this study because you have either expressed an interest in joining the workshop, identify as a member of an underrepresented community or have relevant expertise in this area. We would like to get a wide range of opinions from different people, so any experience and thoughts are appreciated.

Do I have to take part?

No, taking part is voluntary. We will contact you to confirm your interest in participating. You will have a chance to ask any questions you have about taking part.

We will then ask you if you would like to take part in the study.

If you do want to take part, we will let you know the date, time, and location for the workshop.

If you do not want to take part, you will not have to do anything further. We will not contact you again about this study.

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

We would like you to take part in up to eleven workshops. Each workshop will last for about two hours. The workshops will take place in an accessible venue within South Yorkshire.

While we would ideally like participants to attend all sessions, we understand that this may not always be possible due to personal circumstances. Each workshop you attend will contribute valuable information to our research.

In total, we are asking for about ten hours of your time (five workshops), plus any time it takes you to travel to the workshops.

We can pay for your travel costs to come to the workshop. If you need childcare or other support to take part, please let us know and we can discuss arrangements.

Before the workshop, we will go through the consent form with you. **You will be asked to sign the form to confirm that you understand the study and that you are happy to take part.** This is called "giving consent". If you change your mind at this point, you will not have to give consent. You will not have to take part if you don't want to.

At the workshop, you'll meet the research team at the start, and you can speak with them at any time. The workshop will be relaxed and informal. Everyone will be given a chance to speak. There will be no right or wrong answers. We will make sure that everyone feels safe to share their experiences and ideas. Everything that is said will be treated in confidence.

What will I be asked to do at the workshop?

During the workshop, you will be invited to participate in a series of activities to:

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- Help the researchers understand what helps people do the test and what might make it difficult.
- Help us understand what's most important to fix first
- Help design new ways to support people with the FIT test
- Talk about the best ways to deliver this support to your community
- Plan how to make these improvements happen in real life

An agenda will be sent to you before each workshop which will outline the activities and topics to be discussed at the workshop.

Everyone's experience will be important. Even if you don't think you are an expert or know all the answers, your contribution will be really important to us.

The workshops will involve talking about your experience with FIT testing or bowel cancer screening and things that you think might make the process better. You will not need to share anything that you feel uncomfortable about.

To make sure that everyone can contribute, we will also ask you to listen to other people's stories and ideas and to take on board what they are suggesting.

We will audio record the sessions to capture the discussions and mapping process. These recordings will help us analyse the information and may be used to create materials for future workshops.

After the workshop

After the workshop, you will be offered payment for taking part. We will offer you £50 for your participation. This payment will be in addition to any travel expenses.

You do not have to accept any payment. If you receive benefits, accepting payment from us **could** have an impact on the benefits you are eligible for. If you are unsure about this or have any questions, please contact your benefits adviser or Citizens Advice. You can find their nearest office [on their website](#) or by calling 0800 144 8848.

If you have any questions after the workshop, you can contact the project manager using the details provided earlier.

You do not have to take part. You can change your mind about taking part at any point.

If you do take part, you are free to stop at any time without giving a reason.

If you decide to stop taking part during the workshop, you can leave at any time. This will not affect your care or the care of any of your family or friends. However, it may not be possible to remove your input from group activities after the workshop finishes. We will not use any quotes from you.

What are the possible benefits of taking part?

We can't promise you that there will be a direct benefit of taking part. Many people find it rewarding to take part in research because it gives them a chance to help and to improve healthcare for people like them. Coming to the workshops will give you a chance to meet other people and to share your experiences. This can be a helpful experience for many people. You will also be paid £50 for each workshop.

What are the possible disadvantages of taking part?

Taking part will take up approximately two hours of your time for each workshop you attend, plus any travel time. We will reimburse you for any expenses and will offer you payment for your time. We encourage you to commit to attending as many workshops as you are able to. This will not affect your right to withdraw at any time.

Talking about cancer screening and testing may be emotional or difficult. Our team is trained and experienced to support people to talk about these important topics. If you feel that the workshop is becoming overwhelming, you can take a break or stop taking part at any time. You will never be pressured to share anything you are not comfortable with.

Your involvement in this study will be confidential and only members of the research team will know whether or not you have agreed to take part.

During the workshop we will audio record the discussions and take photographs. We will keep these records confidential and they will not be shared outside of the research team. You do not need to be in any photographs if you don't want to.

We will store the records from the workshop securely for five years after the end of the study. After this, they will be destroyed.

We will share findings of the study in scientific journals and/or at conferences, as well as on a website and social media. We will not include your name or any information that could identify you.

What will happen to information collected about me during the study?

We will treat any information you give us in confidence. We will store all your information safely and securely. We will not mention your name in any publications about the study and we will make sure that no individuals can be identified in the study results.

We will keep the information you give us as part of the current study safely for five years after the study ends. It will then be destroyed securely. Paper records will be handled only by

the study team and kept in locked cabinets. Electronic records will be held on a secure computer server approved by the University of Sheffield. Only authorised members of the study team will have access to your information.

At the end of the study, any audio recordings will be destroyed within three months. We may keep your contact details to share updates about the project.

We will be happy to answer any questions you may have about how we use the information we receive from you as part of the study. Please contact the project manager using the details provided earlier.

What if there is a problem?

If you have concerns about the study or if there is anything you would like to ask about the study, please get in touch. (Project Manager: Naseeb Ezaydi. Email: n.ezaydi@sheffield.ac.uk) You can also contact the study lead:

Dr Matthew Kurien (Chief Investigator)

Division of Clinical Medicine

Medical School, University of Sheffield

Sheffield

S10 2RX

Email: m.kurien@sheffield.ac.uk

We do not expect that any harm will come to you from being in this study.

If during the workshop you feel distressed by talking about your lived experience, a member of the team will be available in the room to talk to privately before, during, and after the workshop. For accessing support outside of the workshop, we recommend reaching out to:

- Your GP
- The Samaritans (**phone:** 116 123; **email:** jo@samaritans.org)
- NHS 111 for urgent crisis support and medical advice

If you wish to raise a complaint on how we have handled your personal data, you can contact the University of Sheffield's Data Protection Officer who will investigate the matter.

Luke Thompson (Head of Data Protection and Legal Services)

Email: dataprotection@sheffield.ac.uk

If you wish to contact someone independent of the study on a safeguarding matter or concern regarding the study, you can contact the head of department (Prof. Stephen Renshaw, Head of Division of Clinical Medicine at the University of Sheffield.)

Email: s.a.renshaw@sheffield.ac.uk

What will happen to the results of the study?

When the study has finished and the results have been published, we will send you a summary of the study results if you have agreed for us to do so. You can contact us directly if you decide not to take part in the study but would still like to receive a summary of the results.

The information gathered from the workshops will inform the development of an intervention package. We will write academic papers and reports based on the findings.

Who is organising and funding the study?

The study team is led by Dr Matthew Kurien, a Senior Clinical Lecturer in Gastroenterology who works at the University of Sheffield. The study is part of the PRO-FIT project, which aims to optimise the use of Faecal Immunochemical Testing to enhance bowel cancer detection and address health inequalities. This research is funded by the National Institute of Health Research (NIHR) Programme Development Grants (PDG).

The study has been reviewed by an independent group of people, called a Research Ethics Committee. This is to protect your safety, rights, wellbeing, and dignity. This study was looked at and approved by University of Sheffield, Department of Psychology Research Ethics Committee (Reference number: 067782).

You may want to discuss the information in this letter with a family member or friend. **If you are interested, please complete an expression of interest form.**

Someone from the research team will contact you soon. You will have the chance to ask any questions you have about taking part. If you're happy to go ahead, we will let you know the date and time for the workshop.

Thank you for taking the time to consider taking part in this study.

Data Protection statement

The University of Sheffield is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The University of Sheffield is a publicly funded organisation that conducts research to improve health, care, and services. Research following the UK Policy Framework for Health and Social Care Research is conducted to serve the interests of society as a whole. The legal basis provided under the Data Protection Act 2018 and the UK General Data Protection Regulation upon which we are using your personal information for this research is 'a task carried out in the public interest' and "for research purposes" if sensitive information is collected.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The University of Sheffield will use your name and contact details to contact you about the research study and to oversee the quality of the study. Your name and contact details will be kept separate from the other information that we obtain from you for this research. Your research records will contain a unique code number instead. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The University of Sheffield will keep consent forms and other information about you from this study for 5 years after the study has finished.

Thank you for reading this information.