



PARTICIPANT INFORMATION SHEET

Telling Your Story: The Bowel Cancer Screening Experience

You are being invited to take part in a study about bowel cancer screening. Before you make a decision about taking part, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about it if you wish. If you have any questions about the study, or you would like more information, please feel free to contact the researcher, Dr Lesley McGregor (see contact details at the end of this information sheet).

What is the purpose of the study?

The aim of this study is to collect stories of bowel cancer screening experiences from those who have already taken part in the NHS Bowel Cancer Screening Programme (BCSP). This data will then provide the content of a leaflet that will be used to inform people making the decision to participate in the NHS BCSP or not. The data we collect will also be used for research and teaching purposes within the University College London.

Why have I been chosen?

As somebody who has completed the NHS bowel cancer screening test, your personal experience of this process is of great value to us. You are in a unique position to provide others who are considering taking part in the NHS BCSP, real life examples of the process.

What would taking part involve?

If you take part, you will meet with the researcher, Dr Lesley McGregor, in a place suitable to you (e.g. your home, offices within the University College London, or a quiet room within the BBC office in Teddington). At this meeting you will be asked to sign a consent form and then interviewed about your experience with bowel cancer screening. The interview will be voice recorded and will be made up of 3 parts.

- 1) You will be invited to tell your story about the NHS bowel cancer screening programme, in your own words, without being interrupted.
- 2) The researcher will then ask you questions about points brought up in your story.
- 3) The researcher will ask questions on additional topics related to bowel cancer screening.

The interview is expected to last up to two hours. If necessary, the researcher may decide to do Part 3 on another day suitable to you, either face-to-face or over the phone. At the end of your meeting, if you agree, the researcher will take your photograph to potentially be presented alongside your story. If you wish, you may also provide your own photographs for possible use. These will be posted back to you once a copy has been taken.

Following all three parts, your story will be typed out. If you wish, you can read over your story and make changes or comment on it before submitting it to us for use in our research. Another consent form will be signed at this stage to confirm what information you are happy to have presented with your story (e.g. first name, age). Everyone will receive £20 to compensate for their time and any travel expenses.

Do I have to take part?

No, you do not have to take part in this study. Whether or not you take part in this study is entirely up to you. If you DO NOT wish to be interviewed about your experience with bowel cancer screening that is absolutely fine. We simply ask that, if possible, you let the researcher, Lesley McGregor, know so that we do not contact you again about this study. A decision not to take part, will not affect the standard of care you receive.

If you DO wish to take part please either contact Lesley McGregor directly, or state your willingness to take part to Lesley McGregor when she calls you in a couple of days to confirm you have received this letter. A date and time can be arranged then for you to take part.

If I say that I would like to take part in the research now, can I change my mind later?

Yes, of course. Taking part in this study is voluntary; therefore, if you do decide to take part in the research, you can change your mind at any time. If you do change your mind, please let Lesley McGregor know as soon as possible. You will not be put under any pressure to continue in the research.

What will happen to the information I provide during the interview?

A number of participants will have their story printed in a leaflet to be given to members of the general public who are being invited to take part in an NHS bowel cancer screening programme. The leaflet will be given out in addition to the usual invitation pack from the NHS for a trial period and, if successful, may become part of the invitation pack in the future. Not everyone will have their personal story published in the leaflet. However, all collected stories will be stored for future use by researchers and teaching staff at UCL. If you agree, your photograph, first name, the area in which you live and your current age may be printed alongside your story. Other personal information will be stored securely within offices at UCL.

Results of any analysis involving the stories will be published in academic journals. A summary report will be made available to all interested participants. Whilst quotes from your interview may be included in journal publications, your name will not be.

What information will be held about participants?

The voice recordings of all interviews will be typed out and then deleted. All data will be collected and stored securely in accordance with the Data Protection Act 1998. If you agree, at the end of the research study, a copy of your contact details, story and photograph will be passed on to Beating Bowel Cancer for possible use in media and charity materials. BBC will always contact you before using your data and they too will store your details securely in accordance with the Data Protection Act 1998.

Who has reviewed this study?

This study has been reviewed and approved by UCL Research Ethics Committee (Project ID number: XXX).

What do I do if I wish to make a complaint about the research?

If you are unhappy with any part of the research, please contact either the researcher, Lesley McGregor or the study's Principle Researcher, Dr Christian Von Wagner (contact details are at the end of this letter).

About the researcher:

Dr Lesley McGregor is a Research Associate at the University College London and it is she who will be carrying out the interviews. Lesley would be happy to answer any questions you may have about the study whilst you make your decision regarding participation. Lesley sent you this letter and will call you in the next few days to ask about your decision.

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Thank you for reading this letter and thinking about taking part in this study.