

PARTICIPANT INFORMATION SHEET

Study Title: Attitudes to the NHS Bowel Cancer Screening Programme

We would like to invite you to take part in a research study. Please read this leaflet which tells you about the study and what it involves. You can also ask one of our team if there is anything that is not clear. Take time to decide whether or not you wish to take part.

Why are we doing the study?

The NHS offers screening for bowel cancer. We would like to hear your views about this. We are particularly interested to hear your views if you do not wish to be screened or if you are not sure if you want to be screened. This will help us to design information about the screening programme which allows people to make an informed decision about whether to accept screening or not.

Why have I been chosen?

You are in the age range of people who are invited to take part in the screening programme.

Do I have to take part?

No, you do not have to take part in this research. The decision is entirely up to you. If you decide to take part, we will ask you to sign the consent form attached and to return it to us in the FREEPOST envelope enclosed. If you decide not to take part or you change your mind about taking part, this will not affect your NHS care in any way.

If I did take part what would be involved?

If you agree to take part in this research we will first ask you to complete a short background questionnaire about you. This will allow us to make sure that you join a discussion group of similar people (eg all women).

Taking part in the research would be just like having a chat with a group of people like yourself. Two researchers and about eight people will get together and talk about this subject. The researchers will ask some questions but mostly the members of the group will do the talking. The researchers will be interested in your views and opinions.

The discussion will last about one hour. We will make a voice recording of the discussion so that there is an accurate account of everything that was said.

We will provide food and drinks for you (e.g. biscuits, fruit juice, tea, coffee). We will also give you £20 to cover your travel expenses.

What information will be held about participants?

We will keep a written copy of everything that was said during the group discussion but the names of the group members will be removed. This means that you will be able to talk freely in the group discussion because nobody outside of the group will ever find out who said what.

What will happen to the results of the study?

We will write reports about our findings for everyone who took part and for publication in an academic journal. Our results will also be used as the starting point for a larger study to design more helpful information about the NHS Bowel Cancer Screening Programme.

We will also share a summary of the findings with you if you wish.

To make sure that we give an accurate picture of your views and opinions we may include some direct quotes taken from the group discussion. However, we will never reveal your name in any of our reports.

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

Yes, of course. If you feel unhappy with any aspect of the research (including the way you are treated by the researchers) you can pull out of the study at any time without having to explain your reasons – if you wish to pull out at any time please inform Cecily Palmer or Mary Thomas as soon as possible (**020 7679 5655**). You will not be put under any pressure to continue in the research.

Who has reviewed this study?

This study has been reviewed by South East London Research Ethics Committee 5.

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

If you wish to complain about any aspect of the research, you should contact the Chief Investigator, Professor Rosalind Raine (see below). If you feel you do not receive a satisfactory response and you wish to take the matter further please write to the Research Governance Sponsor, University College London (UCL) (see below), quoting reference 10/0468. All communication will be dealt with in strict confidence

Researchers' contact details

Please think about whether you would like to take part in the study. If you have any questions please get in touch with Cecily Palmer or Mary Thomas who will be happy to answer them.

Researchers: Cecily Palmer and Mary Thomas
ASCEND Study
Health Care Evaluation Group
Department of Epidemiology & Public Health
1-19 Torrington Place
London WC1E 6BT
020 7679 5655
Email: cecily.palmer@ucl.ac.uk or mary.thomas@ucl.ac.uk

Chief Investigator:
Professor Rosalind Raine
Health Care Evaluation Group
Department of Epidemiology & Public Health
1-19 Torrington Place
London WC1E 6BT
☎ 020 7679 1713
✉ r.raine@ucl.ac.uk

Research Governance Sponsor:
Joint UCLH/UCL Biomedical Research Unit
R&D Directorate (Maple House)
Rosenheim Wing
Ground Floor
25 Grafton Way
London WC1E 5DB.

Thank you for thinking about taking part in this study