Participant Information Sheet – People with colorectal cancer

**Study Title**: A focus group enquiry to investigate different stakeholder perceptions of self-management outcomes

**Researchers**: Dr Emma Boger & Dr Jaimie Ellis **Ethics number**: FoHS-Ethics - 8331

**Please read this information carefully before deciding to take part in this research and discuss it with friends, relatives or your GP if you wish. If you are happy to participate you will be asked to sign a consent form.**

**What is the research about?**

We are interested in how people who have had a diagnosis of bowel (colorectal) cancer manage their health and wellbeing. This is called self-management. We are also interested in the ways that health professionals and services help people manage their health and wellbeing. This is called self-management support.

The Government wants health services to provide self-management support but we don’t know what people with bowel cancer, or their family and friends who support them think about self-management support.

This study is interested in finding out your views on what affects you would like self-management to have on your health and well-being and how self-management support should aim to help you achieve this.

**Why have I been chosen?**

You have been chosen because you have had a diagnosis of colorectal (bowel) cancer. People who have had this condition often find they have to manage a number of things for them to stay well, for example fatigue, diet or mood changes. Your experiences of self-management are therefore valuable to this research.

**Do I have to take part?**

No, taking part is voluntary. It is up to you to decide whether or not to take part. If you decide not to take part you do not have to give a reason.

**What will I be asked to do if I take part?**

If you decide to take part, a researcher will contact you to ask some questions and check your suitability for the study. This will take around 10 minutes. You will then be asked to attend a discussion group with other people who have had bowel cancer (maximum 10). You will be asked to sign a consent form.

During the discussion group, you will be asked to talk freely about topics relating to managing your bowel cancer and your health and well-being. The discussion will last between 60-90 minutes. We will break during the session. **The discussion will be tape-recorded and notes will be taken during the session.** If you are concerned that you may have difficulties participating in a group discussion, but would still like to take part, it may be possible to visit you at your home to conduct an interview.

The discussion group will be run by two researchers from the University of Southampton. Light refreshments will be provided.

**What should I do if I want to take part?**

If you would like to take part or would like further information to help you decide, the contact details of the researchers can be found at the bottom of this information sheet.

**What are the possible side effects of taking part?**

The study consists of group discussion therefore we do not expect any side effects. While every effort will be made to avoid upset, there is a possibility that some of the things discussed might be upsetting for you. If you wished to leave the discussion, a researcher would be available to accompany you and make sure you were all right. After the discussion finishes a researcher would be available to give information on possible sources of support or advice.

**What are the possible benefits of taking part?**

There is no personal benefit for you in taking part. However, it is hoped that your participation in the study will enable researchers to understand more about what people want from services that support self-management. Any travel expenses will be reimbursed. You will be offered a £10 WHSmith voucher as an appreciation for giving your time.

**In case of complaint**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Please discuss with the researcher in the first instance to see if the problem can be resolved. If you would prefer not to discuss with the researcher, you should contact Martina Prude, Research Governance Office at the Faculty of Health Sciences (Address: University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7912; Email: [sohsreso@soton.ac.uk](mailto:S.J.S.Rogers@soton.ac.uk)). If you remain unhappy and wish to complain formally, details of the University of Southampton Complaints Procedure will be provided by this office.

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

The research team will not reveal that you have taken part in this study, or what you have said to anyone. Everyone who attends will be asked to maintain the confidentiality of the other people in the discussion group. You do not have to make comments on any topic you don’t feel comfortable with. All information collected will be kept securely and confidentially. Any information concerning you will have your name removed and not be identifiable to you. When the study finishes the study data will be kept securely at the University of Southampton for ten years.

**What will happen to the results of the research study?**

The findings will be used to help researchers understand the things that are important to self-management from the perspectives of people with bowel cancer and their family and friends.

The results may be reported in professional publications or meetings, but you will not be identified by name. You may like to receive a copy of the summary of the research, and can indicate this when you participate.

**Who is funding the research?**

This study is being funded by the Health Foundation, a charity that works to improve the quality of health care in the UK ([www.health.org.uk](http://www.health.org.uk)).

**Who has reviewed the study?**

The University Research Governance department and Faculty of Health Sciences at the University of Southampton have reviewed and approved the study. It has been subject to ethical review by the Faculty of Health Sciences ethics committee.

**What do I do now?**

Thank you for considering taking part in this research. If you would like to take part, please contact the researchers on the Freephone number below, or via email, leaving your name and contact details:

**Freephone: 0800 0285116** (NB If you are calling from a mobile, please omit the first ‘0’)

Emma Boger, Snr Research fellow Jaimie Ellis, Research fellow

email E.J.Boger@soton.ac.uk. Email : J.Ellis@soton.ac.uk

Or return the reply slip below in the freepost envelope provided.

You will be contacted to discuss any queries you may have and arrangements for the group session.

Thank you again for reading this information sheet and for your interest in the study.

**Study Reply Slip** (please return this if you are interested in taking part or require further information)

Name:…………………………………………………………………………………………

I would like to take part in the research study / or require further information to help me decide (delete as appropriate)

Contact details

(telephone/email):………………………………………………………………………………................................

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Any other information (e.g. best times to contact, etc)

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**Further Support and Advice**

The following organisations may be helpful to you should you wish to discuss any issues before, during or after your participation in this study.

**Macmillan 0808 808 00 00** <http://www.macmillan.org.uk/>

Provides information on colon and rectal cancer, including how these cancers are diagnosed, treatments, possible side effects and how to get further support.

**Beating bowel cancer** <http://www.beatingbowelcancer.org/>

**08450 719 301**

A team of nurses support bowel cancer patients and their families by phone, by email, on our forum and through Facebook and Twitter. They provide advice to those who are worried about symptoms, recently diagnosed or living with bowel cancer.

**The Expert Patient Programme** [www.expertpatients.co.uk](file:///\\soton.ac.uk\ude\personalfiles\users\ejb1c09\mydesktop\Health%20Foundation\WP2\ethics\www.expertpatients.co.uk%20%20%20%20)

**0800 988 5550**

Expert Patients Programme Community Interest Company (EPP CIC) provide and deliver free courses aimed at helping people who are living with a long-term health condition to manage their condition better on a daily basis

<http://www.patient.co.uk/>

Patient.co.uk is one of the most trusted medical resources in the UK, supplying evidence based information on a wide range of medical and health topics to patients and health professionals.