Participant Information sheet: information for healthcare professionals

Study title: Are we addressing the longer-term impact of surviving treatment for rectal cancer on gastrointestinal, urinary and sexual function in patients: a cross-sectional view of patients, clinicians and specialist nurses.

(Study ID 189719)

1.1 What is the purpose of the study?

We would like to invite you to participate in our questionnaire study, which aims:

1.To gain perspectives from surgeons and specialist nurses working nationally as to the perceived prevalence of long-term postoperative gastrointestial, bladder and sexual dysfunction in rectal cancer survivors, and how this compares with patients' experience.

2.. To identify what services are currently in place across the UK for rectal cancer survivors

3. To identify what gastrointestinal, urinary and sexual symptoms are commonnly encountered by rectal cancer patients who have had sphincter-preservig surgery.

The main focus of this study is to ascertain at a national level how much consideration to long-term function is currently undertaken by surgeons during the consenting process, and whether this meets our patients needs in the context of getting to grips with the often life-changing consequences of treatment early on in the rehabilitation process. Additionally, in accordance with the National Cancer Survivorship Initiative (NCSI), we wish to identify whether current patient support set-up is sufficient, or whether access to a more streamlined and standardised service is required to help meet our patients needs, both clinically and psychologically. This information will be gathered through the use of three linked online questionnaires; one aimed at patients, another at surgeons and another at colorectal nurse specialists.

1.2 Why have I been invited?

You have been invited to participate either through your Deanery, the Association of Coloproctologists of Great Britain & Ireland, or if you are a colorectal specialist nurse, through your trust email address.

We are looking for healthcare professionals who are regularly involved in the care of rectal cancer patients.

If you are a surgeon or a trainee, we would ask that you are involved in consenting/operating on at least two anterior resections a year.

1.3 Do I have to take part?

No, it is up to you to decide to take part. If you wish to take part, then a link to the questionnaire is at the bottom of this page. If at any point during the questionnaire you decide you no longer wish to participate, then any data you have entered will be deleted when you exit the questionnaire. If you have any questions prior to completing the questionnaire, then you can email one of our researchers on lisaramage@nhs.net.

1.4 What will happen to me if I take part and what will I have to do?

If you would like to take part, you can access the questionnaire online at: (Full website address to be confirmed). The questionnaire should take no more than 10 minutes to complete. By completing the questionnaire, you will not be expected to give any information about your identify. The data you give is therefore **fully anonymous.** We do however ask you to provide details of the region in which you work, in order to help us identify differing needs for service development in specific areas.

We ask that you answer the questions as fully and honestly as possible.

The data you provide as well as those from the patients and other health professionals will be stored securely and be analysed by the research team. The data obtained during the study will be stored securely for a total of 10 years after the study has ended.

1.5 What are the potential benefits of taking part?

This data will be used as evidence towards formulation of national guidelines to the management of the after-effects of rectal cancer treatment through Delphi consensus.

1.6 What happens after the research study stops?

Results will be published via a peer-reviewed journal. If you wish to be contacted separately, then there will be an option to leave an email address at the end of the questionnaire and we will update you with the study findings.

1.7 What if there is a problem?

If you experience any problems or have any questions, please contact us by email at lisaramage@nhs.net. If you have any concerns about how the research is being conducted, then you can contact the Joint Research Compliance Office at Imperial College London: jrco@imperial.ac.uk.

1.8 Will my taking part in the study be kept confidential?

We will not be collecting any information about your identity. We will keep all data collected securely stored and only be used for the purposes of this research.