

PARITY - Prehabilitation for Cancer Surgery: Quality and Inequality

Document #: Participant Information Sheet: PARITY Work package 1: Defining Aims, Objectives and Values

We are a team of researchers at Lancaster University. We would like to let you know about a project we are carrying out funded by the National Institute for Health and Social Care.

The project is looking to address the similarities and differences in support and care that are provided to patients in the NHS before cancer surgery. The project has been approved by Lancaster University Faculty of Health and Medicine Research Ethics Committee (ref:).

Please take time to read this information sheet so you fully understand what involvement in the project will involve.

What is Prehabilitation?

Prehabilitation is the name given to a programme of different activities provided to patients in the NHS before cancer surgery. However, what these activities are and the scientific evidence to support their use before cancer treatment is mixed and often not well explained.

Patients' views on how prehabilitation is delivered vary, and little is known about what patients want from these services. Despite these uncertainties, many areas of the NHS recommend and provide prehabilitation for patients awaiting cancer surgery. Some of these are run across a whole city or region, but many are very small and limited to a particular hospital or even particular types of cancer. Different services are available to different people in different parts of the country, with some people having no suitable services available at all.

What is the study about?

We aim to make a major contribution towards addressing the problem of variation in prehabilitation before cancer surgery. We will work with patients, carers and healthcare professionals to find ways to describe, measure and assess the quality of services. We will also identify and share examples of best practice about how services are developed, funded and delivered.

Why have I been approached?

You have been approached because you have expressed an interest in taking part.

Do I have to take part?

No. It is completely up to you to decide whether or not you take part. You are free to withdraw at any time without giving a reason. If you do decide to take part, please keep this information sheet and contact the research team using the information at the end of the sheet. This information is also available on the summary leaflet you have been given.

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

As part of the research, we are conducting three workshops with people who have lived experience of cancer (including friends and relatives) and healthcare professionals. Each workshop will take no longer than four hours and will include lunch and breaks.

In the first workshop, we will meet with healthcare professionals separately to people with experience of cancer. The other two workshops will be joint.

You will also be asked to complete an on-line questionnaire ahead of the workshops asking you some information about your background, including age, gender and ethnicity. This is so that we can make sure workshop attendance is diverse.

During the workshops, you will be asked to take part in some activities that will help us to understand what is important to people in relation to prehabilitation for cancer surgery. This might involve talking about how people cope with a cancer diagnosis and discussing services that the group have experienced or think would be helpful. The workshops will be facilitated by experienced members of the research team who include designers, psychologists and healthcare practitioners.

There will be no more than 35 people at each workshop, including members of the project team. During the workshops we will take notes and sometimes capture images but we will seek your permission before doing this. You are free to stop at any point during the workshop.

At the end of the third workshop, we will aim to have a prototype of the criteria that might be used to evaluate prehabilitation services for cancer surgery. In the weeks following this workshop you will be sent an on-line questionnaire where you will be asked to rank which criteria are important to you. We will perform this ranking process a number of times (3-5) so that we can reach a consensus between members of the group. This is called a Delphi Process.

If you contact the research team indicating you are happy to take part, we will contact you with the demographics form and a consent form.

We ask that you participate in all three workshops and the Delphi process.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress during the workshop, a private room will be available and a member of the research team will be available to talk to you and provide support. The research team include healthcare professionals with experience of working with people affected by cancer. If you experience any distress following participation, you are encouraged to contact the resources provided at the end of this sheet or contact the research team for further information.

We understand that some people might not feel comfortable or be able to attend a workshop. If you would like to take part but would prefer to feed in your contributions in a different way, we can arrange for you to speak to the project's patient and public involvement coordinator who will facilitate alternative arrangements for you. This might include meeting with them online during or prior to the workshop and your opinions being fed in on your behalf.

Are there any benefits to taking part?

Participation in the workshops should support Continuous Professional Development for healthcare professionals and support the development of inclusive patient care relating to prehabilitation for cancer surgery.

We will pay you for your time in taking part in the workshops and the Delphi Study. We will also reimburse your travel expenses. Payment will follow the guidelines set out by the National Institute for Health and Social Care Research Centre for Engagement and Dissemination. This will be £150 per workshop and £50 for the Delphi Study. This includes payment for attendance and any preparatory work. Preparatory work may include reading some brief materials and making notes ahead of a workshop.

Professionals taking part in the workshops are responsible for arranging any leave needed to facilitate their participation.

Will my data be identifiable?

In the first instance, you will be asked to submit your email address with the information you provide on the pre-workshop survey. Once this has been received, the research team will anonymise your data and separate your responses from your contact information.

Any information you provide during workshops will be fully anonymised. We may use direct quotations from responses but any names or identifiable data will be removed before these are shared.

The data collected for this study will be stored securely:

- The computer files will be encrypted and the computer itself password protected.
- The typed summaries of workshops will be anonymised.
- Photographs taken during workshop breaks will be stored on a password protected computer, with your permission we will use these in dissemination events related to the project. On the consent form, you will be asked if you would prefer for your face to be pixelated.
- Direct quotations from workshops may be used, but your name will not be attached to them.
- Any personal data will be confidential and will be kept separately from workshop responses.

At the end of the project's timeframe, all research data will be kept securely and accessible, according to Lancaster University's Research Data Management policy (a minimum of 10 years).

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researchers.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit: <https://www.lancaster.ac.uk/research/participate-in-research/data-protection-for-research-participants/>

What will happen to the results?

The criteria generated as part of this study will be used in subsequent stages of the research project. It will be used to select which criteria should be used in creating a map of prehabilitation services and will inform the interviews and case studies of services in later stages of the project.

In addition, reports may be submitted for publication in academic and professional journals. Individual participants will be anonymised and attempts will be made to remove any identifiable information in published material. At the end of this stage of the project, we will send you a letter that will include details of the final criteria and the plans for the project.

Who has reviewed the project?

This study has been reviewed and approved by the Lancaster University Faculty of Health and Medicine Research Ethics Committee.

Can I invite other eligible participants to the workshops?

Places at each workshop are limited. However, if you know someone who would like to take part, please pass on the contact information and ask them to get in touch with <<admin>> on the details below. If you have any questions about the study, please contact the project team using the contact information below.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the project team via:

Dr Laura Wareing
Senior Research Associate, Lancaster University
Email: l.e.wareing@lancaster.ac.uk

Dr Yasemin Hirst
Research Fellow, Lancaster University
Email: y.hirst@lancaster.ac.uk

Andrea Partridge
Patient and Public Involvement Lead
Email: Andrea.Partridge@lthtr.nhs.uk

Dr Cliff Shelton
Principal Investigator, Lancaster University
Email: C.Shelton@Lancaster.ac.uk

Lisa Ashmore
Co-Investigator, Lancaster University
Email: L.Ashmore@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to one of the researchers, you can contact:

Dr Jemma Kerns
Research Director
Lancaster Medical School
Lancaster University
LA1 4YG
Email: j.kerns@lancaster.ac.uk

or:

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
Faculty of Health and Medicine
Email: l.machin@lancaster.ac.uk

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resource may be of assistance:

Macmillan Cancer Support provide information, practical and emotional support, advice and listening service for anyone affected by cancer. www.macmillan.org.uk

Maggie's provide free practical, emotional and social support to people with cancer and their family and friends. www.maggies.org

NHS Psychological Therapies Service (IAPT) including talking therapies and help with common mental health problems, like anxiety and depression. <https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/>