



Participant Information Sheet

Prehabilitation for cancer patients who live in a remote, rural or island location in the Highlands of Scotland

Introduction

You are being invited to take part in a project to explore the experiences of people living with cancer during the time between their cancer diagnosis and the start of their treatment.

Before you decide to take part, it is important that you understand why the project is being done and what it will involve. Please take the time to read the following information carefully, if anything you read is unclear, or you would like any further information or to ask any questions, please use the contact details below to get in touch. Please take time to consider whether to take part.

Thank you for your time,

Prof Trish Gorely Prof Nicola Carey

What is the purpose of the project?

This project is being conducted by UHI on behalf of the North Cancer Alliance (NCA). The NCA is a collaboration between the six health boards in the North of Scotland (NHS Grampian, NHS Highland, NHS Tayside, NHS Orkney, NHS Shetland and NHS Western Isles). The goal of the NCA is to improve outcomes for cancer patients.

The NCA is interested in learning more about the benefits and barriers to prehabilitation ('prehab') for cancer patients living in the Highlands and Islands. Prehab takes place in the time between diagnosis and the start of treatment, and aims to help people prepare for their treatment/surgery. It might involve physical activity, diet, lifestyle and/or emotional and wellbeing support.

The aim of this evaluation is to gather the views, opinions and experiences of prehab among cancer patients living in the Highlands and Islands. We plan to talk with up to 40 adults, either in focus groups (with 4-6 people together) or in one-to-one interviews. The information



collected will help NCA inform the design and delivery of prehab services in the Highlands and Islands.

Why have I been contacted?

We are asking adults living in remote and rural areas of the Highlands and Islands who have had a diagnosis and received treatment for cancer between 6 months and 2 years ago to take part in this study. You have been invited to take part because you are in touch with one of the NCA partner organisations or community contacts and identified as a someone who is living with cancer.

Do you have to take part?

No. It is completely up to you whether you take part or not. If you decide not to take part your medical care will not be affected in anyway. If you take part in the study, you will also continue to receive your medical care as normal.

What would taking part involve?

If you agree to take part you can choose between taking part in a focus group with between 3 and 5 other people, all of whom are living with cancer, or in a one-to-one interview. A focus group will last up to one hour, and an interview will last about 30 minutes. Focus groups may be face-to-face or online using MS Teams, interviews may be face-to-face, or by MS Teams or by telephone. Focus groups/interviews will be organised based on your availability and access. The focus groups and interviews will be facilitated by trained members of the evaluation team.

In the focus groups/interviews we will explore what you did while waiting for surgery/treatment to start, any prehabilitation you may have undertaken, how you were feeling during this time, anything you specifically did to prepare for surgery/treatment, and what was helpful/unhelpful.

The focus groups/interviews will be recorded and then transcribed into a written record of the discussion. These will be anonymised and you will not be identifiable within them. Anonymised quotes from the focus groups/interviews may be used in reports and publications coming from this project.

What are the advantages / disadvantages of taking part?



There are no disadvantages other than the time it takes to complete the focus group or interview.

It is possible that some of the topics discussed may cause you distress. You can choose not to answer any question or withdraw without giving a reason. The facilitators are experienced at this type of work with a variety of different patient populations.

You may not benefit directly from taking part, however you will be contributing to a project which looks at an important question. Taking part in this project will allow the North Cancer Alliance to influence the design and delivery of future prehabilitation programmes.

What will happen if I don't want to continue with the project?

You are free to withdraw from the project at any point without giving a reason. Any contributions to the focus group will continue to be used within the project. Contributions to an interview can be withdrawn on request up to the point of analysis. Withdrawing from the project will not affect your medical care.

What happens if something goes wrong?

The risks of participants suffering harm as a result of taking part in this study are minimal. The University of the Highlands and Islands (UHI) has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you wish to discuss any aspect of the way in which you have been approached or treated, or how your information has been handled during this project, you should contact Professor Trish Gorely, email address: trish.gorely@uhi.ac.uk; telephone number 01463 279811.

If you wish to speak to an independent person about the project or make a complaint please contact: Fiona Leiper, Research Ethics Officer University of the Highlands and Islands, IV3 5SQ. email: fiona.leiper@uhi.ac.uk

Will my taking part in this study be kept confidential?

The nature of the study means that the evaluation team will be aware of your involvement. However, all data will be anonymised once recorded. Please see further details about data protection at the end of this information sheet.



What will happen to the results of the research study?

The results of the study will be used to inform the design and delivery of local prehabilitation programmes. The results will be presented locally and may be published in an academic journal. All data will be anonymised and presented in summary form only – it will not be possible to identify you in any report or presentation.

A copy of the results from the finished study can be provided on request by contacting us using the details at the end of this document. The results will be made available as a lay summary, and as a full report.

How long will my data be kept for?

In accordance with UHI policy your data will be retained 5 years. This retention period is in respect of the data as collected. Anonymized data may be kept for longer and the retention period does not apply to any materials published as a result of this project.

Who is organising and funding the research?

The project has been commissioned by the North Cancer Alliance, which is a partnership of the six NHS Health Boards in the North of Scotland. The project is funded by Macmillan under the Transforming Cancer Care Programme for Scotland.

Who has reviewed the study?

This project has been internally reviewed by members of the UHI evaluation team, the North Cancer Alliance, the NHS Highland Research, Development, and Innovation department, and the UHI research ethics committee.

Thank you for reading this form and considering taking part in the study.

What do now?

If you wish to take part, please send an email to nicola.carey@uhi.ac.uk or leave a voice message on 01463 279824. Please leave your name and contact details so that we can get in contact with you to discuss the project further, answer any questions you may have and, confirm your eligibility for participation. Once your participation is confirmed we will send you an online informed consent form to complete and organise your participation in a focus group or interview.



Data protection

Identity of the Data Controller and Data Protection Officer

The data controller is the University of the Highlands and Islands, UHI House, Old Perth Road, Inverness, IV2 3J. The Data Protection Officer can be contacted at:

dataprotectionofficer@uhi.ac.uk.

For questions about the research study please contact: Prof. Trish Gorely (trish.gorely@uhi.ac.uk) or Prof Nicola Carey (nicola.carey@uhi.ac.uk).

Lawful basis for processing personal data:

The lawful basis for processing personal data is: public task. In this case the undertaking of education or research by the University or its students in keeping with the University's public task. This public task includes the planning, delivery, and communication of research. Research includes conducting the research and the taking all required steps to ensure the safety, validity and academic integrity of the research. It may also include re-use of the research data for further research, storage for later inspection, auditing and archiving.

Special category data

The data being used includes special category (sensitive) data about your health. We use this sensitive data under the following legal condition(s): Archiving, research and statistics (with a basis in law). Processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes. That purpose being the undertaking of research by the University.

Your data will or may be shared with the following recipients or categories of recipients:

- The University of the Highlands and Islands and its [Academic Partner Organisations](#), including
- Relevant UHI exam boards comprising UHI and external representatives.
- All individuals to whom UHI considers access should be granted for academic integrity, safety and safeguarding, marking, audit, records management, library,



archiving, and quality assurance purposes (and to ensure all data is handled, and research conducted, in keeping with UHI's policies and procedures). The parties may include UHI staff, contractors or selected external individuals. Such access will only be used as necessary.

- Data may be handled by UHI, or academic partner, ICT or records management staff who are required to undertake actions to keep the data safe, maintain data integrity, or ensure the data is handled and secured in keeping with UHI's data policies and procedures. The parties may include UHI staff, contractors or selected external individuals. Such access will only be used as necessary.
- Service providers providing, under contract, services to UHI that are used for the research purposes such as productivity tools (eg Microsoft Word etc), storage areas, analysis, transcription, or any other service relevant to the research.
- For any questions about data sharing please contact the principal investigator listed in this document.