



Development of an online health and wellbeing programme for patients approaching major surgery

Participant information sheet

We are developing a new, online resource to help patients get ready for surgery and would like your help to build it!

Because you are about to have or have recently had a major operation, we are inviting you to join our development group to tell us what it is you need (or needed) to prepare for surgery. We will also ask you to share your experiences and views of how you have been supported so far, and whether this was useful. This will help us to build the best resource we can for patients like you who are preparing for surgery.

The resource is being designed and built as part of a research study and PhD project. Before you decide if you would like to participate, it is important that you understand why the study is being done and what taking part would involve.

What is the purpose of the study?

We know that patients who have better physical and mental health tend to have an easier journey through major surgery. They experience fewer problems (complications) afterwards and usually recover more quickly.

Helping patients to improve their physical and mental health and wellbeing **before** an operation is known as 'prehabilitation' and could involve:

- Exercising to get fitter
- Stopping smoking
- Cutting down on alcohol
- Eating well
- Sleeping enough and sleeping better
- Concentrating on improving psychological wellbeing

There are lots of ways to support patients to achieve these things. However, most NHS services need patients to attend hospitals or other venues a few times per week to get help.

Many patients have told us they would prefer a different option due to the travel, cost, and inconvenience of such visits. For example, many patients have said they would prefer support they can access when they want and in and around their own home. This has become very important during the recent Covid 19 pandemic.

This support can be provided using an online programme that is monitored by a healthcare professional. It enables patients preparing for surgery to access and use it on their home computers, tablet devices or smartphones. We plan to develop a programme like this for patient to use at home or anywhere they chose.

Involving people preparing for surgery or those who have recently been through major surgery in the development of the programme is important to ensure it is something they want and provides the information they need. It is also important that future patients can use the programme easily and that it will offer them the type of support they need to improve their physical and mental health leading up to their operation.

Why have I been invited to take part?

As someone who is preparing for surgery, or who has recently been through a major operation, you have experience of what it is like to prepare for surgery.

Getting your views during the development of the programme is vital to ensure we build something that is useful for future patients like you.

Do I have to take part?

No, joining the group is completely voluntary. Choosing not to will in no way affect your ongoing medical care.

If you would like to take part, you will be asked to complete a consent form before joining the first group session. If you decide to join but then change your mind, you can leave at any time without giving a reason.

A member of the team will telephone you around 1 week after postage of this information sheet to determine if you would like to take part if you haven't got in touch with us beforehand.

What will participating involve?

There are 3 parts to the study described below. We invite you to take part in just the 1st two or all three parts. Please speak to the study team if you would like more information or to undertake only a particular part of the research:

Part 1. Complete a brief questionnaire (15 minutes)

We will ask you to complete a brief questionnaire to collect some key information about how the online programme should be designed for patients.

Part 2. Take part in an interview (60 minutes)

You will be invited to take part in an interview with a researcher. This will last up to a maximum of 60 minutes. During this interview the researcher will ask you more detailed questions about what type of information and support you would like to receive from the new programme to enable patients to better prepare for surgery. This interview may take place face-to-face, in person at the James Cook University Hospital or York Teaching hospital or from your own home using a video conferencing system like Zoom or Microsoft Teams. The interview will be **audio recorded** to make sure we don't miss anything important that you tell us.

You may like to involve a partner, friend or family member who is supporting or has supported you around your operation in the interview. We would also like to include this person and understand their experiences of helping someone around surgery. If you have someone in mind who might like to do this, **please show them this information sheet** as we will ask them to consent to take part in the recorded sessions so their contribution can be recognised in developing the programme.

Part 3. Join the programme design group

After this you will be invited to take part in **up to six workshops but can participate fewer if you choose**. The workshops will take place either 'face-to-face' at the hospital or remotely by video-conferencing. All face-to-face meetings during the study will be organised in a Covid-safe environment.

Who else will attend the workshops at the same time as me?

Other people taking part in the workshops may include other patients who have recently had major surgery and healthcare professionals involved in the care of patients undergoing surgery. No more than 25 people will attend each workshop.

Representatives from a web development company who are helping us to build the online programme may also be in attendance at some workshops to ensure they can receive and understand your feedback. They have been involved in several projects like this one before and find this really helps them understand what patients need. The representatives will not have access to any of your personal data.

How long will each workshop last and what will it involve?

Each workshop will last up to **2 hours**. Each group will be arranged at convenient times for group members and will be led by at least two members of the research team: Research team members include healthcare professionals, researchers, health behaviour change specialists and representatives from the company who will be building the online programme

During each session we will **ask for the views of group members on how best to design the programme to provide the health and wellbeing support patients require before surgery. To do this we will present information to group members and ask for their views on it. Everything developed will be based on what group members tell us they need to improve their physical and mental health before surgery.** Group participation will involve viewing and testing out early versions of the online programme as it develops to make sure it is useful and easy to use.

Each workshop will **be audio recorded**. We do this so that we don't miss any important information you tell us about the programme. Once we write up the information from the audio recording, we delete it.

You are welcome to bring someone with you to the group sessions (e.g. a partner, family member or friend). If you would like to do this please **give them this information sheet to read** because we will ask them to consent to taking part in the same way as we ask you.

At the end of these workshops, we plan to offer the online programme to other patients preparing for an operation. Once they have used it, we will collect their views.

Expenses and payment for participation.

We will be able to reimburse your expenses (e.g. travel costs, mileage and parking) for every session you attend.

What are the possible advantages and disadvantages of taking part?

Giving up your time to attend and participate in group workshops should be considered.

We also recognise that you may be experiencing a difficult journey toward or recovering from your operation. Discussing issues around this may be stressful or lead to anxiety for some. Please feel free to speak to a team member if this is the case. You do not need to take part in every workshop or stay for the whole workshop if a particular topic is difficult for you.

There is unlikely to be a direct benefit to you from participating. However we hope you will find the experience interesting, informative and that you benefit from the chance to interact with other patients who have had similar experiences to you. The information you give us may also help develop a programme for people like you in the future.

What if there is a problem?

Any complaint you have about participating in this research project will be addressed appropriately. Please discuss this with a team member in the first instance or use the contact details below. If your issue has not been dealt with following this process, you can contact the Patient Advice and Liaison (PALS) service to take this further.

[PALS CONTACT]

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against South Tees Hospitals NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

How will we use information about you?

We will need to use information from you and your medical records for this research project. People will use this information to do the research or to check your records to make sure that the research is being done properly.

This information will include your:

- Name
- Age
- Contact details including a telephone number, address, postcode and email address if you have one
- Biological sex at birth and gender
- Marital status
- Employment status
- Your educational history
- Which internet enabled devices you own, have access to and how often you use them
- How often and for how long you use the internet
- Whether you have used programmes like the one we are building before
- Your previous or upcoming surgery and dates
- Your current physical activity level, smoking status and whether you drink alcohol
- Whether you undertook or are undertaking any activity to improve your health before surgery

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to or calling the study team under 'local study team contact below.

What will happen to the results?

The information you provide during interviews and group workshops will be used to develop the new programme. The process used to develop this programme, including the findings from each stage will be presented at academic conferences and published in academic journals. The research is also part of PhD project anonymous data will be submitted as part of a final thesis.

Who is organizing and funding the study?

South Tees Hospitals, York Teaching Hospitals, Northumbria University and Teesside University are organising the study.

The study is funded by Macmillan Cancer Support and Sport England.

Who has reviewed the study?

The study has approval by North West-Preston research ethics committee (21/NW/0219)

Further information

For further information regarding the study, advice around participation or to discuss a problem please contact the study team or the Chief Investigator:

Your local study team:

[INSERT LOCAL TEAM CONTACT]

Chief Investigators:

Dr Leah Avery

Associate Professor in Applied Health Psychology and Chartered Health Psychologist, School of Health and Life Sciences, Teesside University.

leah.avery@tees.ac.uk

Professor Gerard Danjoux

Professor of Perioperative Medicine, School of Health and Life Sciences, Teesside University and Hull York Medical School, and Consultant in Anaesthesia and Sleep Medicine at the Department of Anaesthesia and Perioperative Medicine, South Tees Hospitals NHS Foundation Trust.

gerard.danjoux@nhs.net

Telephone: 01462 850 850

Department of Anaesthesia

Cheriton House, James Cook University Hospital

Marton Road

Middlesbrough, TS4 3BW