Local NHS Logo

oPtimising post-dischArge care pathways after acute paNcreatitis: evaluatiOn of health seRvice utilisAtion, outcoMes (PANORAMA)

PANORAMA WP4 - Participant Information Sheet

Version 1.1, (11-May-2026)

Invitation to participate in the study

We would like to invite you to take part in a research study sponsored by the University of Birmingham and funded by the National Institute of Health Research. This is being undertaken by the Chief Investigator, Matt Lee, at the University of Birmingham. Before you decide, it's important that you understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

What is the purpose of the study?

Acute pancreatitis is a condition where the pancreas gland is inflamed. People often spend some time in hospital with this. Doctors aren't sure about the best way to support people when they are discharged from hospital. They don't have standards for who needs to be seen in clinic, when they should be seen, or what should be covered in clinic. This means people might not get the support they need. This means they might find ways to look after themselves, or visit their GP or hospital for more support. We want to address this, but first we want to know about peoples' experiences of recovering from acute pancreatitis.

Why have I been invited to take part?

You have been invited because you are being treated in hospital for acute pancreatitis. We would like to understand your care pathway in-hospital and following discharge from hospital. Once you have been discharged from hospital, we would like to ask you a few questions for up to six months through questionnaires.

Who is eligible to take part?

People currently in an NHS hospital with acute pancreatitis can take part.

Do I have to take part?

No, taking part is entirely voluntary. If you agree to take part and later change your mind, you can withdraw (leave the study) at any point without giving a reason. To withdraw from the study, you can contact the study team to let them know of the withdrawal from the study. If you choose to withdraw this will have no impact on the care or treatment you receive, your welfare will remain the priority. It's important that we get as much information as possible so we can work out how to improve care in the future. If you think you are likely to withdraw from the study very quickly, it may be better not to take part.

What will happen to me if I decide to take part?

If you decide to take part you should tell the research team. They will answer any questions you may have, and complete the consent form with you.

They will record some information from your medical notes about your hospital stay for pancreatitis, such as the cause of pancreatitis, what treatments you had for it, and how long you were in hospital for. They will write to your GP to let them know that you are taking part in the study.

Before you go home, we will ask you to complete some questionnaires which tell us about your quality of life, your mental health, and some questions about your gut function. We also ask some questions about alcohol use, and any medical problems you may have.

We will contact you by email, or if you prefer, by post, to complete these questionnaires again at 7 days, 28 days, 3 months, and 6 months after you go home. We will also ask you about how you have used any health care services such as your GP or your hospital in the time since you went home. We hope this will help us to work out who is most likely to come back to hospital following the acute pancreatitis.

It is important to us to get as much information as possible up to 6 months, so we will send you 2 reminders if you don't complete the questionnaires.

When you complete the mental health screening questionnaires, our system will check the answers. If you provide answers that suggest you are at high risk of harming yourself, we will inform your GP who will follow their local safe-guarding procedures and we will advise you to contact them or seek mental health support via 111.

Are there any possible disadvantages or risks from taking part?

There are no anticipated disadvantages from taking part in this study. The questionnaires should not take long to complete.

What are the possible benefits of taking part?

Taking part in the study will not benefit you directly but may help to improve care for patients with similar problems to you in the future.

Will I be reimbursed for taking part?

No, we are not able to offer any payment for taking part in this study.

How will we use information about you?

We will need to use information from you and from your medical records for this research project.

This information includes your:

- Name
- Contact details (telephone number and/or e-mail)
- Demographics (date of birth, sex, ethnicity)
- Medical history
- Self-reports of symptoms including gut function and mental health.

People will use this information to do the research or to check to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

The University of Birmingham is the sponsor of this research.

The University of Birmingham is responsible for looking after your information. We will not share your information related to this research project with any other organisations.

We will keep all information about you safe and secure by:

- Restricting access to your information to just those who need to see it; typically the PANORMA research team at your hospital and the study management team running the study. Sometimes the sponsor or regulatory bodies may wish to review conduct of a study and request access to data. These are the only groups outside the research team who may have direct access to the database.

- Your data is stored on a database at the University of Birmingham. This database is encrypted, and access requires personal passwords and two-factor authentication to take place.

- All activity on the database is logged, so we can see who has added and viewed your data.

International transfers

Your data will not be shared outside the UK.

How will we use information about you after the study ends?

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. We will keep

your study data for a maximum of 10 years. The study data will then be fully anonymised and securely archived or destroyed.

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.
- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

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

You can find out more about how we use your information

- our leaflet (http://www.hra.nhs.uk/patientdataandresearch)
- by asking one of the research team
- by sending an email to panorama-study@contacts.bham.ac.uk
- by ringing us on +44 (0)121 4159106
- the University's Data Protection Officer at dataprotection@contacts.bham.ac.uk

How have patients and the public been involved in this study?

Patients have been consulted on the design of this study and are involved in the management team.

Who has sponsored, insured, reviewed and funded the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given a favourable opinion by the South Central - Oxford B Research Ethics Committee (Ref: 26/SC/0148).

The study is funded by the National Institute of Health Research a UK government-funded body for health and social care research (NIHR number 165210) and is sponsored and insured by the University of Birmingham.

The University of Birmingham has in place Clinical Trials indemnity coverage for this study which provides cover to the University for harm which comes about through the University's, or its staff's, negligence in relation to the design or management of the trial and may alternatively, and at the University's discretion provide cover for non-negligent harm to participants.

What if there is a problem during the study?

If you have any concerns or questions about this study, please discuss with a member of the research team in the first instance, contact details are available towards the end of this sheet.

If you remain unhappy with their reply and wish to make a complaint you can contact your local Patient Advice and Liaison Service. Their contact details are given at the end of this sheet

If you wish to complain about how your information has been handled please contact the University of Birmingham's Data Protection officer via email: dataprotection@contacts.bham.ac.uk

Contact for further information

If you would like any further information, or have any questions concerning this study, please contact:

Mr Matthew Lee at panorama-study@contacts.bham.ac.uk

Department of Applied Health Research, University of Birmingham, Edgbaston, Birmingham, B15 2TT

<Contact Information (for localisation)>

Support can also be found through <NHS Patient Advisory and Liaison Service (PALS); or local equivalent>

Tel: <insert local PALS contact number(s)> Email: <insert local PALS email address>