

Optimising post-discharge care pathways after acute pancreatitis: evaluation of health service utilisation, outcomes (PANORAMA)

PANORAMA WP2 - PARTICIPANT INFORMATION SHEET (CARER)

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. 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 people's experiences of recovering from acute pancreatitis.

Why have I been invited to take part?

You have been invited because you have cared for someone with pancreatitis and have expressed an interest through social media or other online channels.

Who is eligible to take part?

People who have experience of acute pancreatitis (either themselves or caring for someone), cared for in the NHS within the last six months are eligible to 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



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withdraw this will have no impact on the care or treatment provided to the person you care for, their welfare will remain the priority.

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

If you would like to take part, please complete an expression of interest online <<redcap link>>. You will be asked to provide your name, contact details, some details about you, and where in the UK you are based. This will help us to make sure that we capture a range of experiences from around the country. If you are eligible to take part, a member of the research team, will then contact you to answer any questions that you might have and to arrange the interview. If you are not eligible to take part in the study, you will be informed using the contact details you have provided, after which your data will be deleted. If you have told us that you wish to be informed about the results of the study or that you are interested in taking part in other parts of the study, we will keep your contact details until the study is over, after which they will be deleted.

Prior to the interview you will be asked to electronically complete a consent form to agree to take part in the study. The researcher will find a mutually agreeable time for the interview. The interview may take up to 1 hour and will be held by video call (either Zoom or Teams), or by telephone. The researcher will ask you a series of questions related to your experience of care after discharge from hospital. This will include your experience, what support you received, and how you think this could be improved. Before the interview you will have a unique identifier allocated to maintain your privacy and confidentiality. The interview will be audio recorded and a recording of your interview will be provided to an approved transcription service provider to be transcribed. Once the transcription has been received and reviewed by the central research team, the original audio recording of the interview will be deleted.

Are there any possible disadvantages or risks from taking part?

You may find it upsetting to discuss some aspects of your care, but you will only disclose as much as you feel comfortable, and the interview will be paused or stopped if you wish to. If you would like to speak to someone or seek further advice you can contact the patient support organisations.

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 for this research project.

This information includes your:

- Name
- Contact details (telephone number and/or e-mail)
- Demographics (age, sex, ethnicity)
- Region of the UK where you live
- Interview recordings

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 share your information related to this research project with the following types of organisations:

- Other Universities directly involved with PANORAMA (University of Newcastle-upon-Tyne)
- Approved transcription service provider

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 PANORAMA 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 number165210) 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 the Research Governance team at the University of Birmingham by contacting researchgovernance@contacts.bham.ac.uk

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

What do I need to do now?

If you would like to take part in the study please enter this weblink into your internet browser
<<redcap link>>

Contact for further information

If you would like any further information, or have any questions concerning this study, please contact: Mr Matthew Lee by emailing panorama-study@contacts.bham.ac.uk. Department of Applied Health Research, University of Birmingham, Edgbaston, Birmingham, B15 2TT