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RSET rapid service evaluation team

Participant Information Sheet: Patient Interviews (version 1.1 29.03.2023)

Title of Project: Patient-initiated follow-up (PIFU): a rapid study of patient experience and local datasets

The NHS has been changing the way you receive your care as an outpatient. Follow-up appointments have traditionally been offered at routine intervals (e.g. every 6 months) depending on a person's condition. This is changing under a new approach called Patient Initiated Follow-up (PIFU), that is intended to give you and / or your carer more control over your care, by allowing you to arrange your follow-up appointments as and when you need them rather than follow a set schedule. PIFU can also sometimes be referred to as Patient-Initiated Contact (PIC), or open booking appointments.

A team of researchers are studying how PIFU has been introduced in outpatient services, its impact on care, outcomes, and how people experience the service. The researchers are part of the Rapid Service Evaluation Team (RSET), which includes researchers from the Nuffield Trust and University College London. The research team is independent of the PIFU programme and not part of the health care team.

We would like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it will involve. This information sheet provides information about what taking part will involve, how your information and data will be managed, and what to do if you are concerned about your involvement with this study. Please take time to read this information and discuss it with others if you wish. If anything is not clear, or you would like more information, please ask us – our contact details are at the end of this sheet.

What is this study about?

- This study aims to explore the impact of patient-initiated follow-up (PIFU) on patient experiences and outcomes in outpatient services across England.
- As part of this, we are conducting interviews with patients to understand their experience of being offered and receiving PIFU as part of their outpatient care.

This study is part of a larger project, which aims to explore the implementation and impact of PIFU in outpatient services.

Why have I been invited to take part?

You have been invited to take part because you have been identified as someone who has been offered and/or received PIFU as part of your follow-up outpatient care. You may currently be using PIFU or have been offered PIFU but decided not to use it.

We would like to interview you about your experiences of PIFU.

What would taking part involve?

If you decide to take part in the study, we will contact you to organise an interview. The interview will take place over the telephone, Zoom or Microsoft Teams at a time/date that is convenient for you.

You will be given another copy of this information sheet, asked to sign a consent form (either by hand or electronically) and send this to the researcher before the interview.

During the interview, we will ask you about your experience of PIFU as part of your outpatient follow-up care, what worked well or could have worked better, your use of outpatient care and other healthcare services, and your recommendations for improving PIFU services in the future. You do not have to answer any questions you do not want to answer. The interview will last between 30 and 60 minutes, depending on how much you would like to say.

You are free to stop the interview at any time, take breaks or reschedule to another day, or the interview can be split across multiple days.

We will ask for your permission to audio-record the interview. Audio-recordings will be professionally typed up. Any identifiable information (such as names) will be removed. The recordings will be used only for the research team's analysis and no other use will be made of them without your written permission.

Do I have to take part?

No, participation is voluntary and it is entirely up to you whether you would like to take part in the study. If you decide to take part, you will have at least 48 hours in which to consider whether you would like to participate, and you can change your mind and withdraw from the interview at any time. You may also withdraw up to 14 days after the date that your interview took place, without giving any reason, and all of the information you have shared up until that point will be deleted. Withdrawing from the study will not affect your healthcare. If you would like to withdraw from the study, please contact a member of the research team (details are at the end of this information sheet).

Do I have to be interviewed in English?

If you would prefer to conduct the interview in a language other than English, please contact the study team (details are at the end of this information sheet). They will look into conducting the interview with an interpreter if needed, please contact the research team to arrange.

What are the possible benefits of taking part?

There will be no direct benefit to you from participating in this study and no expenses or reimbursements will be provided. However, the information that you provide will help inform and provide learning about implementation of PIFU across hospital Trusts in England, and may help to improve services for other patients in the future.

What are the possible disadvantages of taking part?

There are no known disadvantages in taking part. However, you may find it difficult to discuss your condition and care. If this happens, you are free to stop and/or withdraw from the interview at any time and you can withdraw from the study up to 14 days after the date that your interview took place. If you decide to withdraw from the study, all the information you have provided until that time will be deleted. You may also want to speak to someone outside of the research

team – details of the Patient Advice and Liaison Service (PALS) are provided at the end of this information sheet.

Will my taking part in this project be kept confidential?

Everything you say/report will be confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else. We will not tell anyone that you have taken part in this study or pass your contact details onto anyone else. All information collected during the study will be kept confidential and anonymous. We will ask for your consent for short, anonymised sections of the interview (direct quotes) to be used in written reports, publications, or any other materials produced for the study.

How will we use information about you?

The information you share during the interview will be used to inform our research study and understand the impact that PIFU is having on patients. Personal information (such as your name, email address or phone number) will only be used for the purpose of organising and conducting the interview.

All information will be kept confidential and any information included in our reports will be anonymous.

This information will only be accessed by the research team. Your data will kept safe and secure. Once we have finished the study we will keep some of the information so we can check the results.

What are your choices about how your information is used?

You can stop being part of the interview at any time, without giving a reason. 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 by asking one of the research team (contact details at the end of the information sheet) or by sending an email to data-protection@ucl.ac.uk. The data custodian (and lead researcher) for this study is Dr Angus Ramsay, who has overall responsibility for making sure your data and information is kept safe.

How will my data be stored/managed?

We will record the interview on an encrypted, password-protected digital audio recorder, even if the interview takes place over Teams or Zoom. Only members of the research team will know the password. Recordings and consent forms will be transferred onto a secure computer network and deleted from the recorder. Recordings will be typed up by a professional company, who have a service and confidentiality agreement in place with University College London. Personal information such as names will be removed before analysis takes place. Transcripts may still include information that could identify you.

Identifiable information will not be shared with anyone outside of the research team and will not be included in reports or publications. Apart from the professional transcription company who have access to the recordings, only named team members have access to recordings via password-protected computers, and personal data (i.e. name, email address). Our research team is made up of named individuals from University College London and the Nuffield Trust. Paper-based data (e.g. signed consent forms) will be stored in locked filing cabinets. Your identifiable data will be stored securely for up to three years after the end of the project and then destroyed securely. Anonymised data will be archived for up to 20 years.

What will happen to the results of the research project?

Findings will be shared in a variety of ways including reports, academic publications and presentations, and to a variety of audiences including NHS England. Once published, the study will be made freely and publicly available and you will be able to access the findings on the RSET website: https://www.nuffieldtrust.org.uk/rset-the-rapid-service-evaluation-team#about-rset.

Who is organising and funding the research?

The study is funded by the National Institute for Health Research (NIHR). The study is led by Dr Angus Ramsay, Senior Research Fellow at University College London. The research is being conducted by the NIHR Rapid Service Evaluation Team (RSET) based at University College London and the Nuffield Trust.

Who has reviewed this study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. The London-Chelsea Research Ethics Committee has given a favourable opinion of the study.

What if something goes wrong?

If something goes wrong and you want to make a complaint about the conduct of the research, or would like help or advice following your participation, you can contact the study's principal investigator, Dr Angus Ramsay (angus.ramsay@ucl.ac.uk). If you are not satisfied with the response you receive then you can contact the study Sponsor at the Joint Research Office, UCL: Research-incidents@ucl.ac.uk.

UCL holds insurance against claims from participants for harm caused by their participation in this research. Participants may be able to claim compensation if they can prove that UCL has been negligent.

Who should I contact with questions about the study?

If you have any questions about the study or your involvement, please contact the research team using the details below.

Other information

If you would like to disclose malpractice or poor care, or make a complaint about the care you have received, please contact your local Patient Advice and Liaison Service: https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/

For more general support you may find the following resources useful:

- Your local Healthwatch (find here): https://www.healthwatch.co.uk/your-local-healthwatch/list

Data Protection Privacy Notice.

The data controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and' Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Research team contact details

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Chief investigator: Angus Ramsay, angus.ramsay@ucl.ac.uk or 020 3108 3239
Sarah Reed, Senior Fellow, sarah.reed@nuffieldtrust.org.uk or 0207 462 0521
Rachel Hutchings, Fellow, rachel.hutchings@nuffieldtrust.org.uk
Cyril Lobont, Research Assistant, cyril.lobont@nuffieldtrust.org.uk

Thank you for taking the time to read this information sheet and for considering taking part in this research study. If you take part, you will be given a copy of this information sheet to keep and you will be asked to sign two copies of a consent form - one of which you will keep.