Developing and **E**nhancing the Usefulness of **P**atient **E**xperience and **N**arrative **D**ata

Chief Investigator: Dr Caroline Sanders, University of Manchester

Staff Participant Information Sheet

We would like to invite you to take part in a research study. Before you decide whether or not to take part, please read this information sheet which explains what this research is about, why it is being done and how it could involve you.

What is the study about?

Information about patients' experience of NHS services is routinely collected with the aim of informing ways of improving the quality, safety and effectiveness of services, and ensuring that they are sensitive to population needs. However, there are problems with patient experience data, and the way in which they are processed and summarised. Data often come from postal surveys that ask patients questions about events that took place sometime ago. Not only do these surveys receive low response rates, but healthcare professionals are often sceptical about the relevance of information due to the generalised nature of the questions that are asked, and concern that the views of vulnerable patients and carers may be excluded.

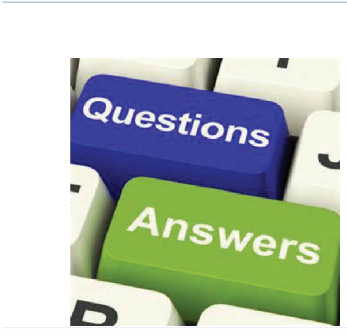
This study asks: can we make data about patient experience of NHS services easier to collect, and more useful, by improving the way we analyse and present this data?

By talking to and working alongside patients, carers and staff this study aims to collect information in 'real-time' – that is, as soon as possible after services have been experienced. We are interested in finding out what information needs to be collected and how best to do this. We also want to look at more efficient ways of analysing the information that patients and carers provide and how to present it in a meaningful way that will enable staff to use in ways that will make a difference to NHS services.

Drawing on these conversations, we will formulate, introduce and train staff to use a toolkit that will provide:

i. guidance about collecting patient feedback
ii. new methods for analysing patient feedback data
iii. new methods and guidance for presenting patient feedback data

This project will focus on the experience of patients with either a musculoskeletal condition or who have experienced serious mental illness, and the staff who support them in one of three settings:



i. the rheumatology outpatients (OPD) within xxxxxxxx
ii. a community mental health team within xxxxxxxxx Trust
iii. one of two general practices

Who is doing the research?

This project is being undertaken by the University of Manchester in collaboration with xxxxxx, and is funded by the Health Services and Delivery Research (HS&DR) Programme of the National Institute for Health Research (NIHR).

Why have I been invited?

You have been invited to participate in this study because you are either:

i. a healthcare professional or other staff member working in xxxxxxxxxx in support of service users with a musculoskeletal condition, or
iv. a mental healthcare professional or other staff member working in xxxxxxxxx
ii. in support of service users a mental health problem, or
iii. a healthcare professional or other member of staff working in a GP practice with experience of supporting patients with either musculoskeletal condition, or a mental health problem.
iv. A member of Information Management & Technology (IM&T) staff in NHS settings included in this study

Do I have to take part?

Participation in this study is entirely voluntary and you are free to withdraw at any point without giving a reason. Should you agree to participate, you will be asked to sign a consent form. Taking part or not taking part will have no effect on your current job.

What will I have to do if I participate?

There are 4 phases (known as 'work streams') to the study. During work streams 1, 3 and 4, members of staff will be invited to take part in either a group discussion or will be interviewed individually by a member of the research team. You will be invited to take part in one interview or focus group discussion when you join the study. You will be invited to take part in either a face-to-face interview, or a telephone interview. Some participants will also be invited to take part in another interview or focus group at later points in the study. You will be invited to take part in a maximum of 3 interviews or focus groups, but you do not need to take part in all of these to be a participant.

In work stream 1, staff will be encouraged to discuss their views and experiences relating to how patient experience data is currently collected. Staff will be asked about the strengths and weaknesses associated with the data that is gathered, the processes used to analyse it and the extent to which the information that emerges is effectively used.

In work stream 2 computer scientists who are members of the research team will design ways to analyse free text comments that are already being collected in the NHS. We are not asking staff to take part in this stage.

In work stream 3, a proportion of staff who took part in initial focus groups and interviews in work stream 1 will be asked to take part in a group discussion to help co-design the toolkit for the NHS that will offer innovative solutions for collecting, analysing and presenting patient feedback data.

In work stream 4, we will introduce the toolkit into the work settings of the teams who participated in the earlier discussions. Staff in each setting will be trained in how to use it and after a period of time, will be asked if they would be willing to take part in an exercise during which they will be observed using the new toolkit. Staff will then be invited to participate in a third group discussion or interview to assess the impact of the toolkit on enhancing the usefulness and relevance of the data collected, the functionality of the toolkit, and its influence on service change.

As part of an economic evaluation of the toolkit, staff will also be invited to take part in a short survey aimed at understanding the time and resources required to use it.

Focus groups will take place at central locations, and individual interviews will take place at a place and time that is convenient for you. We will audio-record these discussions so that we can fully consider and review all that is said. A University of Manchester approved supplier, '1st class secretarial', will transcribe them before we analyse them in our research. 1st class secretarial trades under the name Lawson Hardwick Ltd and has signed a confidentiality agreement with the University of Manchester Website: https://www.1stclass.uk.com/

The focus group discussions will last approximately 1½ - 2 hours. The individual interviews will last approximately 30 minutes.

Will I be paid?

You will not be paid directly for your participation in the study but, as is usual practice, time spent participating in the study will be reimbursed to your NHS trust via support costs agreed by the Comprehensive Local Research Network (CLRN). Your involvement in the research will be during normal working hours and should not change the general requirements of your work or the size of your caseload.

What are the possible disadvantages and risks of taking part?

Because of work commitments you may not be able to take part in all activities. However, you can choose to take part in some or all activities. You can also take a break at any time.

Can I withdraw from the study?

You may withdraw from the study at any point without giving a reason.

What are the possible benefits of taking part?

There are no direct personal benefits to taking part, although you will have the opportunity to participate in research that aims to contribute to the improvement of NHS services by increasing the credibility, usefulness and relevance of patient experience data in services for people with long-term conditions.

What happens when the research study stops?

We will send you a summary of our findings. Please be aware that consent forms, audio recordings and written notes based on interviews and focus groups, will be securely stored at the University of Manchester for a period of ten years.

Will my taking part in the study be kept confidential?

Yes. Whatever you say in interviews or focus groups will be kept confidential and will not be discussed with anyone else. Any information that identifies you will be anonymised or changed to your research ID at the earliest opportunity. Your real name and job title will not be used in anything that we write or publish, although we may provide your generic role e.g. member of clinical staff, nurse, a member of hospital management.

Individuals from the University of Manchester, NHS Trust or regulatory authorities may need to access data collected during this study to ensure the research is being conducted appropriately. With your permission, this will include data from which you could be identified. All individuals have a duty of confidentiality to you as a participant in this research.

What will happen to the results of the research study?

We will make the findings and toolkit available to NHS management nationally and in other hospitals so they can use the results to consider wider implementation and improvement to services in the NHS. We will also publish the results in research publications and inform patient groups about the results.

Your rights:

You should decide on your own whether or not you want to take part in this study. If there are any questions that you do not wish to answer, then you can leave these out. You may stop participating in the study or withdraw some of your data at any time, and this will have no effect on your job.

Ethics Approval:

NHS Research Ethics Committee.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 2674 or 275 2046 or by email to research.complaints@manchester.ac.uk.

Contact Details:

If you wish to discuss participation in the study, any aspects of this information sheet or have any questions or concerns about the study please contact:

Dr Caroline Sanders: Tel: 0161 275 7619
Email: Caroline.Sanders@manchester.ac.uk

Dr Nicola Small: Tel: 0161 275 4844
Email: Nicola.Small@manchester.ac.uk

Dr Papreen Nahar: (Tuesday to Thursday) 0161 275 7640
Email: Papreen.nahar@manchester.ac.uk

Centre for Primary Care
University of Manchester
Williamson Building
Oxford Road
Manchester
M13 9PL

What do I need to do next?

You will be requested to take part in an interview/focus group related to your experience of collecting and using patient feedback within your service area. The interview will be conducted in your convenient place. If any question is unclear to you or if you want to know why are we asking you these questions, you can ask us. It would take about 30 minutes for the interview, and 90 minutes for a focus group. We will take all the care to make you comfortable but if you do not want to continue to talk or want to arrange it another time, we will do that accordingly.

Staff written consent form

Institute of Population Health, The University of Manchester
Williamson Building, Oxford Road, Manchester, M13 9PL
Tel: 0161 275 7619 and/or 0161 275 7640

Study Title: Developing and **E**nhancing the Usefulness of **P**atient **E**xperience and **N**arrative **D**ata **(DEPEND)**
Chief Investigator: Dr Caroline Sanders

➢ Please **initial** the box if you agree with the statement:

1. I confirm that I have read and understand the information sheet (dated…….. v……) for the above study and have had the opportunity to ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that the DEPEND team will hold my contact details so that I can be contacted during the project to arrange my participation in study activities. ☐
4. I understand that I may be invited to consent to participate in up to three interviews or group discussions, and I am happy to be contacted for this purpose. ☐
5. I give consent for any interviews or group discussions that I participate in to be audio recorded and transcribed. ☐
6. I agree to the use of anonymised quotations from interviews being reported in research reports, journal articles and presentations. ☐
7. I understand that later in the study (during Work Stream 4) I will be asked to attend a training session relating to the use of a toolkit designed to enhance the collection, analysis and presentation of patient satisfaction data and I am happy to be contacted for this purpose. ☐
8. Later in the study (during Work Stream 4) I am willing to allow a researcher observe me in the work place. ☐
9. I understand that I will be invited later in the study (during Work Stream 4) to complete a short survey relating to the economic evaluation of the toolkit that will be introduced as part of the study, and I am happy to be contacted for this purpose. ☐
10. I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the relevant NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
11. I understand that when this research is completed the audio file will be retained and securely archived for a period of 10 years. This archive can only be accessed by request from the research team and all files will be destroyed at the end of that period. ☐
12. Would you like to be contacted again with either (a) participation in a further stages of the project ☐ (b) the final results of the study ☐ (c) other similar studies. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature