Appendix 1 – Participant information sheet for patients

Invitation to patients to take part in an independent study "Impact of patient experience data on acute NHS hospital trusts'

We would like to invite you to participate in an interview about your views and experiences related to the collection, analysis and use of patient experience data in the NHS.

What is the study about?

Good patient experience is a key aspect of good healthcare in the NHS. Hospitals often use surveys, questionnaires or forms to find out about patient experience so that they can improve the services they provide.

We are carrying out an independent study of how NHS acute trusts collect, analyse and use this information. We will be talking to frontline staff, hospital managers and patients, and we are particularly interested in the journeys that the data make through different parts of the hospital administration. With your help, we will make practical recommendations to the hospital about how to improve the collection, analysis and use of patient experience data.

What would my taking part involve?

If you decide to take part in our study, we will arrange an interview at a time convenient to you. The interview will take up to 45 minutes, depending on the time you have available. With your permission, we would like to audio record the interview.

Our interview with you will cover the following topics:

- your past and current experience of giving feedback on your patient experience e.g. what feedback you provided, how you provided it and to whom;
- what changes you have seen or would like to see as a result of your feedback;
- your views on the ways feedback is collected from patients and whether this could be improved.

Your participation is entirely voluntary. If you decide later (even during the interview itself) that you do not wish to continue, then you are free to withdraw at any time without giving a reason. With your permission, if you withdraw from the study, or if anything happens to you which means you are no longer able to give informed consent we would like to continue to use any information you have given us up to that time. Your care or treatment will not be affected if you decide not to take part. You can eventually contact us up to February 2018 to request we don't use the information you will provide during the interview.

It is likely that the staff in this ward will know if you take part in an interview. However, everything you say will be treated as confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

We will anonymise all data. This means that if we use extracts from the interview in any presentations or publications, we will not use your name, and we will do all we can to ensure neither you nor the Trust where you have been treated can be identified.

In accordance with King's College London's policy, on completion of the study all the information you have shared with us will be stored in a password-protected archive file on a secure King's College London drive for up to 7 years and will be accessible only to members of our research team. After 7 years, all the data we have collected from you will be destroyed.

Taking part in the study may not help you directly. But we will learn from your experience to make recommendations on how to improve the collection, analysis, and use of patient experience data. We hope this will lead to improvements in the quality of care.

We would like to offer you a £15 shopping voucher as a token of our appreciation of your time and involvement.

What if there's 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. Please see their contact details below. If you remain unhappy and wish to complain formally, you can do this through the Patient Advice and Liaison Service (PALS), [INSERT TRUST PALS CONTACT DETAILS]

In the event that something does go wrong and you are harmed during the research then you may have grounds for legal action for compensation against King's College London but you may have to pay your legal costs. King's College London maintains adequate insurance to cover any liabilities arising from the study.

Who is organising and funding the research?

Our study is funded by the National Institute for Health Research's Health Service and Delivery Research programme (Study ID 14/156/08), and is led by Dr Sara Donetto and Professor Glenn Robert, King's College London.

The study has been approved by the London – London Bridge Research Ethics Committee, and the Health Research Authority.

Further information and contact details

If you would like further information or to discuss this study please contact the researcher for this site [insert name and contact details of researcher at this site]:

If you are unhappy about any aspect of the study you are invited to contact the Principal Investigator Dr Glenn Robert, King's College London, Florence Nightingale Faculty of Nursing & Midwifery,

James Clerk Maxwell Building, 57 Waterloo Road, London SE1 8WA. Telephone 02078483048 or Email glenn.roberts@kcl.ac.uk

The study is funded by the National Institute for Health Research's Health Services and Delivery Research Programme

NHS National Institute for Health Research

Study Title	Exploring the impact of patient experience data in acute NHS hospital trusts in England: using Actor-Network Theory to optimise organisational strategies and practices for improving patients' experiences of care
IRAS no.	188882
Document ID	

Appendix 2 – Participant information sheet for staff interviews and observations

Invitation to staff to take part in an independent study 'Impact of patient experience data on acute NHS hospital trusts'

We would like to invite you to participate in an interview and/or observational research about your views, experiences and routine practices related to the collection, analysis and use of patient experience data at your hospital.

What is the study about?

We are carrying out an independent study of the way in which NHS acute Trusts in England use patient experience data to identify and implement improvements in healthcare quality. In particular, we want to hear about how patient experience data is organized and managed in your Trust; what kind of data are collected and what tools are used to gather, analyse and report them; what kind of "journeys" patient experience data make after they are collected and how they are turned into concrete improvements; what your opinions about the potential of patient experience data are and how you think their collection, analysis and implementation could be improved.

With your help, our study will contribute to improving patient, carer and staff experience of hospital care by generating practical recommendations on how to optimise organisational strategies and practices for the collection, validation, and use of patient experience data.

What would my taking part involve?

In order to keep any disruption to work on the ward to a minimum we are likely to use a mix of one-to-one, paired or group interviews. We will check with you first which of those settings you are happy to be interviewed and/or observed in. If you decide to take part we will arrange an interview or observation times with you at a time convenient to you. The interview will take up to 90 minutes, depending on the number of interviewees and the time you have available. With your permission, we would like to audio record the interview.

Our interviews will cover topics such as:

- your experience with patient experience data;
- the current organizational practices related to patient experience data collection, analysis and use in your ward/Trust;
- your views on its usefulness and what you think is hindering or helping the implementation of improvements based on these data;

- Your views on how the staff and general public are involved in the communication and the implementation of patient experience data.

Staff with particular responsibilities for patient experience data work will also be invited to take part in observational research of routine practice. This will be a researcher 'shadowing' you, intermittently, for under 3 hours during your work day. The researcher will take notes of what s/he has observed. We will take care to arrange for observation to be at times and time periods convenient and comfortable for you and in a way that minimise interruptions to your work. For those staff who are specialists in patient experience data management we might request a further observation of different routine practices as the study progresses. Our total observation time with any one member of staff will not exceed 12 hours in total.

Our observations of practice will help us to understand how you collect, organise, discuss and disseminate patient experience data, and the sorts of effects that patient experience data has on your work and work decisions.

Your participation in the study is entirely voluntary. You can decide to participate in only one part of the study (interview or observation). You might also decide to participate in only one period of observation of routine practice. If you decide later (even during the interview or observation itself) that you do not wish to continue, then you are free to withdraw at any time without giving a reason. With your permission, if you withdraw from the study, or if anything happens to you which means you are no longer able to give informed consent, we would like to continue to use any information you have given us up to that time. You can eventually contact us up to January 2018 to request we don't use the information you will provide during the interview or the observations.

It is likely that other staff will know if you take part in an interview or observations. However, everything you say will be treated as confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else. If you are interviewed or observed with other members of staff we will request that you respect confidentiality for each other.

We will anonymise all data. This means that if we use extracts from the interview or observation notes in any presentations or publications, we will not use your name, and we will do all we can to ensure neither you nor the Trust you work for can be identified.

In accordance with King's College London's policy, on completion of the study all the information you have shared with us will be stored in a password-protected archive file on a secure King's College London drive for up to 7 years and will be accessible only to members of our research team. After 7 years, all the data we have collected from you will be destroyed.

Taking part in the study may not help you directly. But we hope to learn from your experience to make recommendations on how to how to optimise organisational strategies and practices for the collection, analysis, and use of patient experience data, including the effects on staff and what support they may need to implement meaningful change.

Who is organising and funding the research?

The study is funded by the National Institute for Health Research's Health Service and Delivery Research programme (Study ID 14/156/08), and is led by Dr Sara Donetto and Professor Glenn Robert, King's College London.

The study has been approved by the London - London Bridge Research Ethics Committee, and the Health Research Authority.

Further information and contact details

If you would like further information or to discuss this study please contact the researcher [insert name and contact details of researcher at this site]:

If you are unhappy about any aspect of the study you are invited to contact the Principal Investigator Professor Glenn Robert, Florence Nightingale Faculty of Nursing & Midwifery, King's College London,

James Clerk Maxwell Building, 57 Waterloo Road, London SE1 8WA. Telephone 020 7848 3048 or Email glenn.robert@kcl.ac.uk

The study is funded by the National Institute for Health Research's Health Services and Delivery Research Programme

NHS National Institute for Health Research

Study Title	Exploring the impact of patient experience data in acute NHS hospital trusts in England: using Actor-Network Theory to optimise organisational strategies and practices for improving patients' experiences of care
IRAS no.	188882
Document ID	

Appendix 3 - Patient Participant Consent for Interview

Consent to take part in an interview on the 'Impact of patient experience data on acute NHS hospital trusts' study

Please initial each box

1. I confirm that I have read and understand the Participant Information Sheet (Patient Information Sheet phase 1 Version1.6/6/16.IRASID188882) for the above study. I have had the opportunity to consider the information, 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 before January 2018 without giving any reason. ☐
3. If I withdraw from the study, or become unable to give ongoing informed consent, I am happy for the information that I have given before such time to be used in the research. ☐
4. I am happy for the interview to be audio-recorded. ☐
5. I agree that, in accordance with King's College London's policy, on completion of the study notes, audio-files and transcripts of this interview will be stored in a password-protected archive file on a secure King's College London drive for up to 7 years. These files will be accessible only to the members of this study's research team. After 7 years, all data will be destroyed. ☐
6. I understand that what I say will remain confidential, and (for paired or group interviews) I undertake to maintain the confidentiality of other research participants. ☐
7. I understand that any quotes that are subsequently used for reports or publications will not be attributable to me or the organization. ☐
8. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of researcher	Date	Signature

The study is funded by the National Institute for Health Research's Health Services and Delivery Research Programme

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Appendix 4 - Participant Consent for Photograph

Consent form for pictures taken during the 'Impact of patient experience data on acute NHS hospital trusts' study

Please initial each box

1. I confirm that I am happy for my photographs to be taken and used as part of the above study. ☐

2. I understand that my participation is voluntary and that I am free to withdraw consent at any time before September 2017 without giving any reason. ☐

3. If I withdraw from the study, or become unable to give on-going informed consent, I am happy for the pictures taken before such time to be used in the research. ☐

4. I understand that my identity will be anonymized unless I agree otherwise. ☐

5. I agree that, in accordance with King's College London's policy, on completion of the study all the pictures taken of me will be stored in a password-protected archive file on a secure King's College London drive for up to 7 years and will be accessible only to members of the current research team. I understand that, after 7 years, all the pictures taken of me will be destroyed. ☐

6. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of researcher	Date	Signature

The study is funded by the National Institute for Health Research's Health Services and Delivery Research Programme

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Appendix 5 - Staff Participant Consent for Interview

Consent to take part in an interview on the 'Impact of patient experience data on acute NHS hospital trusts' study

Please initial each box

1. I confirm that I have read and understand the Participant Information Sheet [Staff Information Sheet phase 1 Version2.12/10/16.IRASID188882] for the above study. I have had the opportunity to consider the information, 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 before February 2018 without giving any reason. ☐
3. If I withdraw from the study, or become unable to give ongoing informed consent, I am happy for the information that I have given before such time to be used in the research. ☐
4. I am happy for the interview to be audio-recorded. ☐
5. I agree that, in accordance with King's College London's policy, on completion of the study notes, audio-files and transcripts of this interview will be stored in a password-protected archive file on a secure King's College London drive for up to 7 years. These files will be accessible only to the members of this study's research team. After 7 years, all data will be destroyed. ☐
6. I understand that what I say will remain confidential, and (for paired or group interviews) I undertake to maintain the confidentiality of other research participants. ☐
7. I understand that any quotes that are subsequently used for reports or publications will not be attributable to me or the organization. ☐
8. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of researcher	Date	Signature

The study is funded by the National Institute for Health Research's Health Services and Delivery Research Programme

NHS National Institute for Health Research

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Appendix 6 - Patient Consent for Observation

Consent to take part in individual practice observation for 'Impact of patient experience data on acute NHS hospital trusts' study

Please initial each box

1. I confirm that I have read and understand the Participant Information Sheet [Staff Information Sheet phase 1 Version2.12/10/16.IRASID188882] for the above study. I have had the opportunity to consider the information, 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 before September 2017 without giving any reason. ☐
3. If I withdraw from the study, or become unable to give ongoing informed consent, I am happy for the information that I have given before such time to be used in the research. ☐
4. I am happy for the researcher to take anonymised notes of what s/he observes. ☐
5. I agree that, in accordance with King's College London's policy, on completion of the study notes, all notes taken of practice observations will be stored in a password-protected archive file on a secure King's College London drive for up to 7 years. These files will be accessible only to the members of this study's research team. After 7 years, all data will be destroyed. ☐
6. I understand that what I say will remain confidential, and (if group activities are observed) I undertake to maintain the confidentiality of other research participants. ☐
7. I understand that any quotes that are subsequently used for reports or publications will not be attributable to me or the organization. ☐
8. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of researcher	Date	Signature

The study is funded by the National Institute for Health Research's Health Services and Delivery Research Programme

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Appendix 7 - Document release consent form

Consent / Receipt form
Study exploring the impact of patient experience data in acute NHS hospital trusts in England.

The following documents have been given to the King's College Researcher for use in an independent (NIHR-funded) study exploring the impact of patient experience data in acute HHS hospital trusts in England.

In releasing these documents I understand that the documents will be anonymised by the research team, and that if used in any presentations, written reports or papers neither the Trust nor any individuals will be identifiable.

Type of document	Description of documents	Name of Trust staff member	Job title of Trust staff member	Signature of Trust staff member	Signature of researcher
1.Patient Experience Documents; Data Sets; Presentations & Feedback to/from Trusts, Divisions and Services					
National Inpatient Survey					
Cancer Patient Experience Survey					
Outpatient Survey					
'Friends and Family' Test					
Real-time Data					
Complaints/ Compliments					
Patient Stories					
Websites (NHS Choices /Patient Opinion)					
2. Case-study examples of use of patient experience data (eg. for QI work ; CQC inspection; Peer-Review)					
Reports / Presentations					
Other					

If you would like further information or to discuss this study please contact Dr Amit Desai, King's College London, Florence Nightingale Faculty of Nursing & Midwifery, James Clerk Maxwell Building, 57 Waterloo Road, London SE1 8WA. Telephone 0207 848 3527 or email amit.desai@kcl.ac.uk

If you are unhappy about any aspect of the study you are invited to contact the Principal Investigator Professor Glenn Robert at the above address. Or telephone 0207 848 3063 or email