Health Research Authority

FULL/LONG TITLE OF THE STUDY

Use and usefulness of patient experience data: national survey of patient experience leads in NHS acute trusts

SHORT TITLE

National Survey of Patient Experience Leads

PROTOCOL VERSION NUMBER AND DATE

Version 1; 14th October 2015

RESEARCH REFERENCE NUMBERS

IRAS Number:	192500
ETHICS Reference:	[Insert MS IDREC/CUREC approval reference]
SPONSORS Number:	11741
FUNDER'S Number:	HSDR 14/156/06

This protocol has regard for the HRA guidance

The authors declare there are no potential conflicts of interest.

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

Chief Investigator:

Date: 15.10.15

Signature: .....

.....

Name: (please print):

Louise Locock

KEY STUDY CONTACTS

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STUDY SUMMARY

Study Title	Use and usefulness of patient experience data: national survey of patient experience leads in NHS acute trusts
Study Design	Online survey
Study Participants	Patient experience lead or chief nurse from all NHS acute Trusts in England
Planned Size of Sample (if applicable)	160
Follow up duration (if applicable)	None
Planned Study Period	3 months
Research Question/Aim(s)	We will conduct an online survey with the chief nurse or other designated patient experience lead in all NHS acute trusts in England. This is part of a wider study on how to support NHS frontline staff in using patient experience data for improvement. The survey findings will help us put together a national picture of how acute trusts are currently working with patient experience data, and help us identify case studies for phase 2 of the wider study.

ROLE OF STUDY SPONSOR

The Sponsor will assume legal responsibility for initiation and management of the study, and provide insurance cover for the study.

PROTOCOL CONTRIBUTORS

Principal Investigator: Louise Locock, Director of Applied Research, Health Experiences Research Group, Nuffield Department of Primary Care Health Sciences, University of Oxford.

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Survey to be conducted by: Picker Institute Europe

KEY WORDS: Patient experience, online survey, NHS staff, quality improvement

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STUDY PROTOCOL
Use and usefulness of patient experience data: national survey of patient experience leads in NHS acute trusts

1 BACKGROUND AND RATIONALE

Patient experience - alongside patient safety and clinical effectiveness - is a key component of quality of care. It is important both as an end in itself, and because positive patient experience has been shown to be correlated with other clinical and organisational outcomes. Improving patient experience is thus a priority for the NHS, which has led the way in developing measures of patient experience such as the NHS Inpatient Survey. There is a considerable body of quantitative and qualitative evidence on what matters to patients and how they experience care. However, whilst the Inpatient Survey shows small incremental improvements in some aspects of experience, the pace of change remains slow on some of the most important questions for person-centred care. There is a need to move beyond collecting patient experience data to using it to improve care, but the evidence for the most effective ways to do this remains weak. We know little about how frontline staff make sense of, or contest the data, what supports or hinders them in making person-centred improvements and what motivates staff - and patients and families - to get involved in improvement work.

This protocol describes a national staff survey which will be carried out to inform a wider study of how frontline NHS staff can best be supported to use patient experience data for service improvement. The chief nurse or other designated patient experience lead in all NHS acute Trusts will be surveyed about what patient experience data they currently collect, how often, and whether and how the data are used for improvement.

The Picker Institute will use the findings, combined with other publicly available survey data (for example the NHS Inpatient survey) to put together an assessment of trusts' current performance on patient experience and group trusts into a matrix of categories of performance on and operational practice around patient experience, as a sampling frame from which to select 6 trusts for the ethnographic case studies we will conduct in the next phase of the research. This second phase of the research is not included in this protocol and will be the subject of a separate NHS Ethics application.

We are working with a team of researchers from King's College London and Cardiff University studying the ‘journeys’ of patient experience data through NHS organizations as part of a separate NIHR-funded study; at the funder’s request, the findings from this survey will also be used to help this team with their research.

2 RESEARCH QUESTION/OBJECTIVE

In order to understand what patient experience data Trusts currently collect, we will conduct an online survey with the chief nurse or other designated patient experience lead in all NHS acute trusts in England. This survey will ask what experience data they currently collect, how often, and whether and how the data are used for quality improvement. The results will provide evidence about how trusts approach and respond to issues relating to patient experience.

2.1 Outcome

The results will be combined with existing data from the NHS Adult Inpatient Survey; NHS Staff Survey questions on patient experience; Friends and Family Test; and Patient Opinion usage data to investigate how trusts a) perform on these measures and b) organise themselves to work on patient experience and respond to patient experience data. Trusts will be grouped into categories of performance in a matrix which will be used as a sampling frame for future ethnographic case study research to improve the use of patient experience data in the NHS. A similar sampling frame will be developed and supplied to colleagues at King’s College London and Cardiff University.

3 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

This will be an online survey with staff contacted via email. Staff will be identified from records the Picker Institute holds as contractor for the patient survey programme. The survey will go to the chief nurse or other designated patient experience lead in all acute trusts in England (anticipated sample of approximately160). A pre-approach email will inform them of the survey, its purpose and offer a chance to opt-out, with the participant information sheet as an attachment. A follow-up email with a link to the survey will be sent 2-3 days later with the participant information sheet provided again. A reminder will be sent to non-respondents after 1 week. The survey should take about 20 minutes to complete.

The Picker Institute will analyse the responses in combination with existing data as specified above. The aim is to gather summary-level data from these sources into a matrix to identify which trusts consistently demonstrate high performance and strong engagement with patient experience, and those with more mixed performance. [This stage will inform selection of 6 case study sites for the next phase of the research not included in this protocol.] Software to be used includes; Snap 11 Professional to administer the survey online and collect responses; Microsoft Excel 2013 for data management and some basic analysis and IBM SPSS v22 for additional analysis.

For our colleagues at King's College London and Cardiff University, the Picker Institute will group trusts according to their answers to questions 5 and 6 only (specific questions on cancer care and dementia). Results from these two items will be used to create a single grouping variable that categorises trusts according to their levels of activity around measuring and using patient experiences of cancer care and dementia. A list of the trusts in each category will be supplied to researchers at King's College London and Cardiff University to support their selection of sites for a separate HS&DR funded study. The data provided will not contain case-level response data or any confidential information.

4 STUDY SETTING, SAMPLE AND RECRUITMENT

4.1 Eligibility Criteria and sample

Staff will be identified as the 'survey lead' for their organisation in surveys co-ordinated by the Picker Institute as part of the Care Quality Commission's national patient survey programme (anticipated sample, approximately160).

4.2 Recruitment

Before being sent a link to the survey, potential staff participants will be sent an email with a participant information sheet explaining the study. At this point, if they do not wish to take part, they can ask not to be sent a link to the survey, and will have an opportunity to email back with questions. A follow-up email with a link to the survey will be sent 2-3 days later. Again it will be stressed that they do not have to take part. Clicking on the link to the survey will first take them to a page with the content of the participant information sheet repeated. There will then be a link to the questions at the end of the information. A reminder will be sent to non-respondents after 1 week.

4.3 Consent

Participants will be informed that completing the survey constitutes implied consent. The survey will include an 'opt out' button allowing the respondent to withdraw their response data from the survey and alerts us that their responses should be disregarded. Participants will be advised of this in the Participant Information Sheet (PIS) sent in the pre-approach email. The PIS will be sent again with the survey. The PIS contains the contact details of the principal investigator to whom queries may be addressed.

4.4 Discontinuation/Withdrawal of Participants from Study

Each participant has the right to withdraw from the study at any time. (In addition, the Investigator may discontinue a participant from the study at any time if the Investigator considers it necessary for any reason.

Withdrawal from the study will result in exclusion of the data for that participant from the analysis.

The reason for withdrawal by researcher (and by participant, if this information is volunteered) will be recorded in a study file.

4.5 Definition of End of Study

The end of study is the date the last participant completes the questionnaire.

5 QUALITY ASSURANCE PROCEDURES

The study may be monitored, or audited in accordance with the current approved protocol, GCP, relevant regulations and standard operating procedures.

6 ETHICAL AND REGULATORY CONSIDERATIONS

There are no significant ethical issues around conducting the online questionnaire. Participants are advised in the PIS how their personal data and the results of the survey will be used and stored in the research. The PIS is sent to participants as an attachment in the pre-approach email and provided again at the beginning of the survey. Participation is voluntary. The survey will include an 'opt out' button allowing the respondent to withdraw their response data from the survey. This will alert the research team that their responses should be disregarded.

6.1 Assessment and management of risk

We do not think there are any risks in taking part. This is an optional online survey which will include an 'opt out' button allowing the respondent to withdraw their response data from the survey.

6.2 Research Ethics Committee (REC) review & reports

The protocol, participant information sheet and any proposed advertising material will be submitted to The Central University Research Ethics Committee (CUREC), and host institution(s) for written approval.

6.3 Peer review

The study was subject to independent, external peer review as part of the competitive funding application (NIHR HS&DR call 14/156).

6.4 Patient & Public Involvement

Our patient research partner Jennifer Bostock is a co-applicant on the wider project. At outline stage she reviewed the application, edited the lay summary, and made changes in the overall programme of work. She

played an equal role in preparing the full proposal, will remain actively involved throughout and contribute to dissemination. Her involvement will be primarily in phase 2 of the wider study

We are advertising for patient, carer and public advisers to sit on the Study Steering Committee which will oversee the overall programme of work.

6.6 Protocol compliance

As this is an optional online survey, it is highly unlikely that deviations from the protocol will occur.

6.7 Data protection and staff confidentiality

Individual participant data will be held securely and confidentially by the Picker Institute (custodian) in accordance with the requirements of the Data Protection Act 1998 and will not be shared with other co-investigators. The Picker Institute has United Kingdom Accreditation Service (UKAS) accredited certification for its information security management system (ISO27001:2013). The responses will be linked to individual acute Trusts through unique links sent to each participant. The response data will be destroyed after 10 years.

For the purpose of the study led by colleagues at King's College London and Cardiff University, the Picker Institute will group trusts according to their answers to questions 5 and 6 only (specific questions on cancer care and dementia) and supply this information to help them identify possible case studies. The data provided will not contain case-level response data or any confidential information.

Direct access to data will be granted to authorised representatives from the Sponsor or host institution for monitoring and/or audit of the study to ensure compliance with regulations.

6.8 Indemnity

The University of Oxford maintains Public Liability and Professional Liability insurance which will operate in this respect.

6.9 Amendments

The Principal Investigator will submit and obtain approval from CUREC for all amendments to the original approved documents. The sponsor and the Health Research Authority will be notified.

6.10 Access to the final study dataset

Individual participant data will be held securely and confidentially by the Picker Institute and not shared with other co-investigators. Chris Graham, Jenny King and Esther Ainley have received ISO training that includes the safe handling of identifiable data and are experienced in designing studies that meet ethical requirements and have obtained ethical approval for a number of large scale studies. Additionally, they have received mandatory training on safeguarding children and vulnerable adults. Further information security training (ISO27001) was delivered on 13th October 2015 by Protective Intelligence (company number 5299306).

7 DISSEMINATION

It is unlikely that the results from this study will be published in their own right. The survey will help us put together a national picture regarding collection and use of patient experience data, a discussion of which will be included in the final report to the funder. The results will be used to help us identify possible case studies for the

next phase of our work, working with trusts on using patient experience data for service improvement and evaluating how they get on; and to help colleagues at King's College London and Cardiff University do the same. The data will be owned by the Picker Institute