1. Introduction

This Standard Operating Procedure (SOP) describes the procedures to be implemented within the research community when using the National Institute for Health and Care Research (NIHR) Participants in Research Experience Survey (PRES) on UHL sites.

1.0.1)
Every year, the NIHR Clinical Research Network (CRN) asks thousands of participants to give feedback on their experience of taking part in research It demonstrates to research participants that their contribution is valued, and helps research teams identify and improve ways in which research studies are designed and delivered, now and in the future. It will support Research and Innovation (R&I) at UHL to better understand the make-up of our participants so that we can take steps where necessary to make sure that our research outputs are representative of our diverse communities.

2. Scope

This SOP applies to all research activity hosted by the University Hospitals of Leicester NHS Trust (UHL) that implements the NIHR PRES. The PRES should be used in all studies taking place in UHL and in studies hosted by the NIHR Leicester Biomedical Research Centre, NIHR Leicester Clinical Research Facility and NIHR Patient Recruitment Centre: Leicester, unless there is a valid reason not to do so. An example of a valid reason is when a patient is consented by proxy because they are in a coma. A field has been added to collect this information in EDGE (Mandatory 1) and will be audited as relevant.

3. Version control of PRES

The correct version of the PRES can be found in appendix 1. The PRES is updated annually by the National CRN team and is implemented in line with the new financial year.

3.0.1)
The PRES may NOT be localised. Questions are set nationally and cannot be added to or removed from the document. This is to make sure comparisons can be made between studies, teams, organisations and year-on-year.

4. Distributing the PRES to participants

The PRES will be distributed by the study team primarily in paper form in participant study packs, with the study name, site and CPMS number (if available) pre-populated by the study team. This method produces the greatest response rates. It is the study team's decision when the most appropriate point in the study would be to share the PRES, but it must be at the same visit for all participants in the study. Paper versions of the PRES can be ordered directly from the NIHR CRN East Midlands communications team using this online form: https://docs.google.com/forms/d/e/1FAIpQLSeyFxVTxvb51i87JBdLId_Jib3gdw5V7ws8vNwRy_jUg1Hqog/viewform.

4.0.1)
Each study team must reference their study location correctly to support data capture and analysis. The site codes are UHL = RWE; PRC = NIHRPRC005, BRC=BRC6, CRF = CRF29.

4.0.2)
A Perspex box will be provided by the NIHR CRN East Midlands to research areas on request, where participants can insert completed surveys. It is the study team's responsibility to empty this periodically and send completed surveys to the national Clinical Research Network for input

into the database. When folded and sealed, the surveys display the freepost address on the front. Freepost envelopes are not required Participants maywish to take the survey away to complete at home.

4.1)
Digital PRES
The study team may choose to ask participants to complete the PRES online, provided they have the means to support participants to do so, such as a tablet. The link to the PRES online version is here: https://crnem.typeform.com/to/uSNgSxih?typeform-source=www.google.com

4.2)
Multiple responses from the same participant
A participant should only receive the PRES once, at the allocated study visit, in accordance with the delivery plans of the study team. If participants wish to provide further feedback at later visits, they may scan the QR code on the PRES poster provided as Appendix 2. This poster can be printed, laminated and then populated with the study name, site name and CPMS number using a whiteboard marker. Alternatively, study teams can request bespoke posters with a QR code and unique link from the NIHR CRN East Midlands communications team using this online form: https://docs.google.com/forms/d/e/1FAIpQLSds2AsN5HRKvQvsp3Vvdne6KvBvz3EGnuYraDdrXMKt6NkJNg/viewform

4.3)
Additional resources
Further resources to support you to implement PRES can be found on the PRES resources website: https://sites.google.com/nihr.ac.uk/crneastmidspres/for-research-professionals/pres-resources. You will need an NIHR account to access these resources. If no one in your team has an NIHR account, then please contact the research communications team for support at researchcomm@uhl-tr.nhs.uk.

5. Using the feedback to improve service provision

In agreement with the NIHR CRN East Midlands, data from completed surveys will be uploaded into the analysis tool one month from receipt. If negative comments are received, study teams may be contacted by the NIHR CRN East Midlands to notify them of the issue to enable the team to respond in real time. Results can be viewed on the live dashboard here: https://www.leicestershospitals.nhs.uk/aboutus/education-and-research/leicesters-research/get-involved/pres/

5.1)
Feedback from the surveys will be used to demonstrate that UHL research listens to its participants and acts on their input to improve the quality of our services. With support from the Research Communications team, study teams can create Patient Engagement boards, 'You Said, We Did' cards to share on social media and in participant correspondence, and use for discussion in team meetings. Information from the PRES can also be used to support dissemination of results, as evidence in annual reports, and in future grant applications.

6. Responsibilities

	Responsibility	Undertaken by	Activity
1	UHL R&I	R&I corporate senior leadership team	Make informed decisions based on patient feedback where it applies to more than one speciality/study type or where an investment is required across the service.
2	UHL R&I	R&I Head of Communications (HoC)	Provide report on PRES responses to R&I Executive and support study teams with participant engagement.
3	CMG/ Specialties	Research Teams	Make informed decisions based on patient feedback where actions can be taken at study/specialty level

4	CRN	CRN	Upload PRES responses to the dashboard and inform of negative comments in 'real time' to speed up response. Provide information about the breakdown of performance by study, specialty or NIHR infrastructure as requested by HoC
5	R&I Office	Research Manager	Include information in feasibility form, to prompt study teams to consider when they will provide the PRES to their participants.

7. Who Guideline Applies To

This guideline applies to all staff within UHL and external to UHL who are delivering research at Leicester's Hospitals.

8. Guideline Standards and Procedures

The SOP is detailed so the process can be clearly followed. No flowchart is provided / required.

9. Education and Training

None.

10. Monitoring Compliance

What will be measured to monitor compliance	How will compliance be monitored	Monitoring Lead	Frequency	Reporting arrangements
Sponsor Audit	Randomly chosen for audit out of studies using the PRES	Head of Research Communications	Annual basis	A report will be taken to R&I Executive

11. Supporting Documents and Key References

SOP C-2033 Appendices 1, 2 & 3

12. Key Words

Research, Innovation, Feasibility, PRES, Survey, Feedback, Patient Experience

13. Contact and Review Details

CONTACT AND REVIEW DETAILS	
Guideline Lead (Name and Title) Rachael Dowling, Head of Research Communications	**Executive Lead** **Medical director**
Details of Changes made during review: **Review and update** **Submit new to PGC**	

14.

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This table is used to track the development and approval of the document and any changes made on revised / reviewed versions

DEVELOPMENT AND APPROVAL RECORD FOR THIS DOCUMENT		
Author / Lead Officer:	Rachael Dowling	**Job Title:** Head of Research Communications
Reviewed by:	UHL R&I Governance Meeting	
Approved by:	Professor Nigel Brunskill DocuSigned by: Nigel Brunskill EB83FF9A871E447...	**Date Approved:** 17-01-2022

REVIEW RECORD			
Date	**Issue No.**	**Reviewed By**	**Description Of Changes (If Any)**
Nov 2021	1	RD, LW	New SOP
April 2022	2	RD, LW	PRES will be used for all UHL research studies without a valid reason not to do so; the PRES document has been updated for 2022-23.

DISTRIBUTION RECORD:			
Date	**Name**	**Dept.**	**Received**

Roll over and stick to page 3

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Would you like to hear more?

Please tick the option(s) as appropriate:

I would like to receive the results of this survey ◯

I would like to receive updates about research opportunities ◯
e.g. a newsletter. You can unsubscribe at any time

Name: ______

Email address: ______

If you do not have an active email address or prefer to be contacted via post please provide your home address:

______

For staff use:

Study name/acronym:

NIHR research site ID code (required):

Study IRAS/CPMS number (required):

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Freepost RUEA-EHSX-SKYX
NIHR PRES
PO Box 168
Brighton
BN41 9EU

NIHR | National Institute for Health and Care Research

Thank you for taking part in research.

Please tell us about your experience.

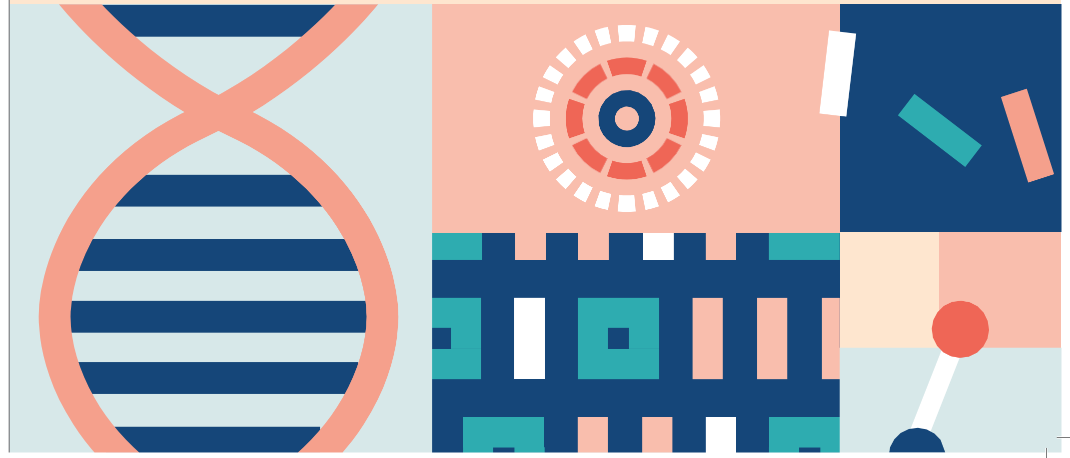
We are asking you to complete this survey because you have previously or are currently taking part in research supported by the National Institute for Health and Care Research (NIHR). We fund and support research in the NHS as well as public health and social care research.

We want to make research better so that people like you have the best experience possible. We would value your feedback to help us do this.

Once you've filled out the survey, remove the perforated section, then fold and stick the survey as directed. Use any postbox to return - no stamp required.

You can also complete this survey online at: http://bit.ly/crneastmidlandspres

w: http://bit.ly/crneastmidlandspres
e: crneastmidlands@nihr.ac.uk
t: 0116 258 6185



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About the survey

Taking part in the survey is voluntary. The survey usually takes up to five minutes to complete. There are no right or wrong answers to any of the questions. It will not affect the care or treatment you receive, whether or not you choose to leave feedback.

Privacy and Data Protection

This anonymous survey is being undertaken on behalf of the NIHR and as such, any information collected will be subject to the terms of use and protections as outlined in the NIHR Privacy Policy (www.nihr.ac.uk/documents/nihr-privacy-policy/12242). Your responses and comments will be shared anonymously with the NIHR and any healthcare providers (e.g. GP practice/hospital) involved in the research study you are/have been part of. No identifiable data will be shared with any third party.

Should you choose to provide your contact details as you want to receive the survey results or want to find out more about participating in research, these details will be stored separately from your survey responses before any analysis of responses is undertaken, thereby maintaining the anonymity of the survey. If you complete a paper version of this survey, your contact details and survey responses will be stored separately in an electronic format and your paper survey will be securely destroyed.

We may use your comments in reports about research and for promotional activities, but we will remove any information that does/could identify you before publishing any of your feedback.

Please rate how **strongly** you **disagree** or **agree** with the following statements about your research experience. Tick inside the face or circle that matches your answer best. Please think about the research you are currently taking part in, or have most recently taken part in.

Tear here

Tear here

Moisten here

The information that I received before taking part prepared me for my experience on the study

Strongly disagree | Disagree | Neither agree nor Disagree | Agree | Strongly Agree | I don't remember

I feel I have been kept updated about this research study

Strongly disagree | Disagree | Neither agree nor Disagree | Agree | Strongly Agree | It is too early to tell

I know how I will receive the results of this research study

No ◯ Yes, to some extent ◯ Yes ◯

I know how to contact someone from the research team if I have any questions or concerns

Strongly disagree | Disagree | Neither agree nor Disagree | Agree | Strongly Agree

I feel research staff have valued my taking part in this research study

Strongly disagree | Disagree | Neither agree nor Disagree | Agree | Strongly Agree

Research staff have always treated me with courtesy and respect

Strongly disagree | Disagree | Neither agree nor Disagree | Agree | Strongly Agree

I would consider taking part in research again

Strongly disagree | Disagree | Neither agree nor Disagree | Agree | Strongly Agree

Moisten here

Moisten here

Moisten here

Please use the boxes below to explain your answers to the previous questions or provide any other feedback on your experience in this research.

To maintain your anonymity, please do not share any information in these boxes that could identify you e.g. name, specific conditions/rare conditions.

What was positive about your research experience?

What would have made your research experience better?

How long have you been taking part in this research study?

Less than three months ◯
At least three months but less than one year ◯
At least one year but less than three years ◯
Three years or longer ◯
Not sure ◯

Is this the first research study you have taken part in?

Yes ◯ No ◯

Who completed this survey?

The person taking part in the research ◯
The person taking part in the research with help from someone else ◯
Someone else on behalf of the person taking part in the research ◯

Moisten here

Moisten here and stick to page 4

More about you.

The following questions help us to understand if any groups of people are having better or worse experiences of research than others. Knowing this helps us take action to make sure everyone has the same quality of experience when they take part in research. You do not have to answer these questions. The answers you give will be stored anonymously and separately from any contact details you may choose to share and your answers will not be shared identifiably with any third party.

What is your year of birth? Please write in – e.g . 1964

Prefer not to say ◯

What sex were you registered at birth?

Female ◯ Male ◯ Prefer not to say ◯

Is your gender the same as the sex you were registered at birth?

Yes ◯ No ◯ Prefer not to say ◯

What is your ethnic group? Choose one section from A to E, then tick the appropriate circle to indicate your ethnic group.

A. Asian/ Asian British

Indian ◯ Pakistani ◯ Bangladeshi ◯ Chinese ◯ Any other Asian background ◯

B. Black/ African/ Caribbean/ Black British

African ◯ Caribbean ◯ Any other Black/ African/ Caribbean background ◯

C. Mixed/ Multiple ethnic groups

White and Black Caribbean ◯ White and Black African ◯ White and Asian ◯
Any other mixed/ Multiple ethnic backgrounds ◯

D. White

English/ Welsh/ Scottish/ Northern Irish/ British ◯ Irish ◯
Gypsy or Irish Traveller ◯ Any other White background ◯

E. Other Ethnic Groups

Arab ◯ Other, please write in:

Prefer not to say ◯

Moisten here and stick to page 4

Moisten here and stick to page 4

NIHR | Clinical Research Network East Midlands

NHS University Hospitals of Leicester NHS Trust

Have you taken part in research?

Would you like to tell us about your experience?

Please give us your feedback by completing our Participant in Research Experience Survey

Scan the QR code, or access the survey at:

http://bit.ly/crneastmidlandspres