REPORT OF THE RESEARCH PARTICIPANT EXPERIENCE SURVEY 2018/19

National data collection, analysis and recommendations

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What this Report is about?

This report shares results of the Research Participant Experience Survey 2018-19. The survey is about the experience of participants in health research. Individuals were surveyed between April 2018 and March 2019.

The survey has been conducted annually by the National Institute of Health Research since 2015-16. It is carried out to help continually improve the experience of taking part in health research. It gives participants to chance to feedback on what went well and what could be improved and this report is produced and shared with a wide range of stakeholders in the health research community,

This year the title of the report has changed from ‘Patient Research Experience Survey’ to ‘Research Participant Experience Survey’. This is because individuals that take part in research are typically referred to as ‘participants’ and may not necessarily be patients.

A note on the terms used in the report

Where the expression ‘n=x’ is used it means the number of people who answered that question. For example, ‘n=807’ means 807 answered the question.

Participants: an individual who took part in a health research study

Respondents: individuals who filled in this survey to feedback on their experience of participating in health research

Acknowledgements

The 15 Local Clinical Research Networks and their NHS Partner organisations are thanked for their work in coordinating the delivery and analysis of the survey locally.

Huge thanks are also given to the participants who took part in health research and who completed this survey about their experience.

As a result of the efforts of both of these groups, responses rates to this survey have more than doubled from the previous year.
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1. Introduction

The NIHR oversaw the recruitment of over three quarters of a million participants to more than five thousand studies during 2018/19. Ensuring the experience of these participants is positive, so that more people take part in health research and those who have taken part before want to do so again, is of great importance to the NIHR. Carrying out this annual survey of participant experience is a key way we understand what participant experience in health research is like, and how we can make it better.

The Research Participant Experience Survey is a way of involving participants in the improvement of the design and delivery of health research. The survey is conducted in a way that provides both high level national trends and locally detailed information about participant experience. To achieve this, nationally standardised questions are agreed annually and incorporated by the 15 LCRNs who conduct the survey, along with locally agreed questions within their network. This report is of the three nationally standardised questions. LCRNs produce their own reports covering other local questions.

From 2019-20, this survey of participant experience has been made a Higher Level Objective by the Department of Health and Social Care (DHSC)- this is in recognition of the importance of participant experience of feedback to both the DHSC and the NIHR.

This elevation of the profile of the Research Participant Experience Survey takes place in a wider context of increasing appreciation of the importance of access to research being routinely promoted in the provision of health care. This includes that for the first time in 2018 the Care Quality Commission (CQC) asked patients participating in their Inpatient Survey whether they had been approached about taking part in research during their stay.

The Research Participant Experience Survey has been conducted annually by the NIHR Clinical Research Network since 2015-16. In 2018-19, the response rate of 8,507 constitutes more than a doubling of responses from 2016-17. However, the response rate for 2018-19 is still only around 1% of total participants in NIHR supported studies across the same timeframe. To achieve a long term ambition of offering every participant in research the chance to feedback about their experience, over the coming year the CRN will be exploring ways to develop the way the survey is run so response rates can continue to increase. This report includes a short section on issues with the current survey, and outlines the initial step in addressing these.
2. Executive Summary

The Research Participant Experience Survey is an annual survey which collects feedback from individuals about their experience of taking part in health research. There were 8,507 respondents to the Research Participant Experience Survey in 2018-19. The survey is conducted by the NIHR’s 15 Local Clinical Research Network and their NHS partner organisations and includes three questions which are nationally standardised across all LCRNs, and locally determined questions. This report is of responses to the three national questions across all 15 networks.

Of the respondents:

- 90% reported they would agree or strongly agree that they had a good experience of taking part in research
- 93% reported they would agree or strongly agree they were given all the information needed in relation to the study

Issues impacting participant experience of research

Participants in health research are partners in the research process. We cannot conduct research without them. Understanding the experience of participants in health research and working with them to improve how we design and carry out research to offer a better experience to them and new participants in future is critical. The Research Participant Experience Survey aims to collect such feedback and share it across the health research community to help improve future research.

The results from the 2018-19 survey, as well as previous surveys, highlight five important factors which have a significant role in shaping participant research experience. All of those involved in the design and delivery of health research are encouraged to work with patients and the public to understand these factors locally and to plan improvements to the way research designed and delivered. The five factors are organised into two categories: Design and Delivery.

Design

The two factors in the design category are: participant motivation and benefits and research intervention. The survey shows it is important to consider both of these factors when designing research in order to ensure that there is wide and equitable access to the study across eligible participants and that participants have as positive experience as possible of taking part. These factors are not wholly in the control of sites delivering studies but poor consideration of them during research design can be mitigated by some extent by how site teams deliver the research. Involving patients and public in the earliest stages of research design is a key way of understanding possible participant motivations, benefits and barriers to studies, and of understanding how research interventions ay be experienced by participants.
Delivery

The three factors that shape participant research within the ‘delivery’ category are:

- **Research staff**: staff are central to participant experience and strongly influence the relatedness participants feel to the study itself
- **Study information**: participants having access to the right information at the right time throughout the study process, including after it ends
- **Study organisation and environment**: the more logistical issues around research design which can shape participant experience of a study

**Research Intervention**: The research intervention was referred to specifically at times. It is important to note that feedback is from participants across a wide range of types of research design from observational (e.g. questionnaires etc) to interventional (e.g. clinical trials involving medical procedures). This range represents significant differences in direct impact on participants and therefore how they experienced the study overall. Mentions varied, but most often it was to do with how much it helped the individual or how it was problematic e.g. unpleasant side effects of an intervention.

**Participant motivation and benefits**: The majority of mentions concerned participants recognition that they received better monitoring for their health issues as a consequence of taking part in a study, while a smaller number mentioned how they hoped their participation would help others.

**Research Staff**: Comments most referred to the friendliness, professionalism, knowledge, availability, informativeness, helpfulness, and respectfulness of staff. This reinforces the importance of research staff in shaping participant’s experience of research.

**Study information**: Information was the most frequently mentioned theme in the open text responses: approximately 80% of comments referred to information about the study. This is likely to be because the survey specifically asked about access to information. The majority of mentions focussed on having information in the right place at the right time and having someone available to answer any questions. This clearly impacted on how well participants felt engaged with the studies they were on. Mentions included information given prior to and immediately after consenting, information during the study, and information about the end results of the study.

**Study organisation and environment**: This themes incorporates feedback on how generally well-organised a study was, as well as feedback on specific aspects of the logistics of taking part including time management and access issues like parking and expenses being paid for example. With regards to environment, a small number of comments referred to the general environment in which visits/tests/clinics were being carried out in relation to a study. e.g. whether it was noisy/pleasant/comfortable etc. and indicates that such factors are also a key determinant of the quality of participant experience.

The relationship between these six factors is depicted in the diagram on page 6.
Recommendations

There are opportunities to improve participant experience across the study life cycle. The following table summarises these and they are presented in further detail in section five.

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Insight from survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure site research staff are supported and have sufficient time allocated to build excellent working relationships with patients taking part in the study.</td>
<td>The relationship with research staff is absolutely key to the experience of study participants.</td>
</tr>
</tbody>
</table>
| Ensure the right information is available in the right place at the right time as participants proceed through the study. | Having good timely information is important to people feeling engaged in and valued as participants in a study. Consider methods e.g.  
  • Verbal  
  • Written  
  • Online  
  • Messaging  
  • Video  
  • Responsive (to questions) |
<table>
<thead>
<tr>
<th>Actively appreciate the <strong>motivation</strong> of patients for joining a study and be prepared to explain health issues.</th>
<th>People participate in studies for a range of individual reasons. Understanding a person’s motivation for participating can help you to help them feel fully engaged.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carefully consider participant’s pathway through consenting and starting a study to subsequent study ‘visits’ in the way the study and sites are <strong>organised</strong></td>
<td>People’s time, access, costs, etc. are important to them and should be respected. <strong>Walkthroughs</strong> by patient representatives before starting site recruitment proper, help identify difficulties sooner rather than later.</td>
</tr>
<tr>
<td>Carefully consider the effects of the <strong>environment</strong> participants will be moving through</td>
<td>The general environment will affect how a participant feels about the study.</td>
</tr>
</tbody>
</table>
3. Approach and respondents

Survey design

This report shares responses to the Participant Research Experience Survey. Responses were collected between April 2018 and March 2019. The survey is conducted by the NIHR’s 15 Local Clinical Research Networks in partnership with the NHS organisations where N(HR supported studies are carried out. The networks’ surveys include three nationally standardised questions incorporated by all 15 LCRNs, as well local questions developed by each LCRN with their partner organisations. The three nationally standardised questions LCRNs were required to include in their surveys for 2018-19 were:

<table>
<thead>
<tr>
<th>No.</th>
<th>Type of Question</th>
<th>Question/Statement</th>
<th>Format/options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5pt Rating scale</td>
<td>I was given all the information I needed in relation to the study</td>
<td>Rate on the scale, where 1=Strongly disagree and 5=Strongly agree</td>
</tr>
<tr>
<td>2</td>
<td>5pt Rating Scale</td>
<td>I had a good experience of taking part in the research study.</td>
<td>Rate on the scale, where 1=Strongly disagree and 5=Strongly agree</td>
</tr>
<tr>
<td>3</td>
<td>Freetext</td>
<td>Use this space to tell us more about your answers.</td>
<td>Text box</td>
</tr>
</tbody>
</table>

Some LCRNs changed the sequence of these questions which may have influenced respondent’s answers. In addition, collection methods varied across LCRNs and included both paper and digital responses, as well as postal and face to face collection- see appendix 1 for further information. All of these differences could affect the way respondents answered the questions.

Survey respondents

Across the 15 networks, 8,507 survey responses were collected. Respondents were aged over 18 and had taken part in health research within the twelve months prior to completing the survey. As there was not nationally set criteria for who could take part in the survey, respondents will include both those who have just begun to take part in a study, those who have completed taking part and those in between. Feedback is also from participants across a wide range of types of research design from observational to interventional.

Demographic data, such as age, gender and ethnicity of respondents is not collected in the survey and so not included in this report.

It is important to note that respondents to this survey only included those who had chosen to take part in health research and who were willing to give feedback. These groups may not represent the experiences and views of people who didn’t want to take part in research in the first place or who dropped out of a study and didn’t get the chance to give feedback.
Survey analysis

The question ‘I was given all the information I needed in relation to the study’ was not included in past versions of the survey and was included in 2018-19 as ‘information’ had been a very common feedback theme in 2017-18 and so we wanted to know more about it. Because a question was included on study information, it was mentioned by a very high number of respondents in the open text question.

The approach to analysis was to thematically code open text responses. Responses on the theme of study information were grouped and separately analysed. Other themes were then ordered by frequency of mentions to provide an understanding of most significant topics for respondents. The two ordinal questions (those with the agree/disagree scale) had non-responses removed and are presented in this report by frequency of respondents selecting each option on the scale from strongly disagree to strongly agree.

Other information

Seven LCRNs also conducted children and young people’s survey, gathering responses from 943 respondents across these surveys. As these surveys were not nationally standardised the results are not incorporated in this report.
4. Full report

4.1 Participant experience of taking part in research

The chart below shows responses to the statement ‘I had a good experience of taking part in the research study’

As this question was asked in 2017-18 it is possible to compare responses across the two years:

<table>
<thead>
<tr>
<th>“I had a good experience of taking part in the research Study”.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(5 point scale/ agree + strongly agree)</td>
</tr>
<tr>
<td>2017/18 survey</td>
</tr>
<tr>
<td>n = 4,312 responses</td>
</tr>
<tr>
<td>2018/19 survey</td>
</tr>
<tr>
<td>n = 8,507 responses</td>
</tr>
</tbody>
</table>

It is not possible to draw definite conclusions as to whether this represents a net improvement in research participant experience over the period of a year because of the different ways the
survey is conducted locally each year, but it is very encouraging. This year’s figure is backed up by the higher number of survey responses in 2018/19.

4.2 Study information

Information was asked about as a specific question in the 2018-19 survey as it had emerged as a key topic in open text responses in the 2017-18 survey and we wanted to understand more about how it shaped participant experience. Of the respondents to the 2018-19 survey, the significant majority (93%) agreed they were given all the information they needed in relation to the study (see chart below). However, it is important to note that any potential participants who decided not to take part due to poor quality or lack of information will not be included in survey respondents.

Around 45% of comments to the open text question (n=1,544) were about information. This section introduces a thematic analysis of comments about study information, organised against stages of the research process.

Analysis shows that good information is important at all stages of a study and after the study is completed. It also shows that information is important to participants in a number of ways including:

- Quality (e.g. timely, accurate, clear, accessible and relevant)
- Format balance (e.g verbal, written, video, online, messaging)
- Scheduled and planned (e.g. updates, operational etc.)
- Responsive (e.g. to questions)
Survey responses show that participants have different needs and expectations, and a certain amount of flexibility is needed.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Agree/Strongly Agree responses</th>
<th>Disagree/Strongly Disagree responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early stage information</td>
<td>“I was given the Participant Information Sheet beforehand to read. This was explained at my appointment and I was given the opportunity to ask questions before giving my consent to participate.”</td>
<td>“We were told about the trial by our doctor and CNS nurses but was not told we had to contact the research team to take part. As I wanted to take part it delayed my treatment starting.”</td>
</tr>
<tr>
<td></td>
<td>“Information sheets are clear and easy to understand; doctors are happy to answer any questions and call to clarify medical history if anything was unclear to ensure the best knowledge and care can be provided.”</td>
<td>“I didn’t like the language attached - recruitment, sponsor, randomise.”</td>
</tr>
<tr>
<td>Throughout the study</td>
<td>“Everything was explained very well and if there was anything I didn’t understand the staff were very patient with me making sure I did.”</td>
<td>“If everything could be explained to me. I don’t have a computer and have only seen Dr X once.”</td>
</tr>
<tr>
<td></td>
<td>“There was a lot of reading but all the answers there. It is good to return to the reading material from time to time. I do feel I am contributing to improved care for future generations.”</td>
<td>“I don’t know quite what it is all about - I really believed someone was going to keep in touch.”</td>
</tr>
<tr>
<td></td>
<td>“I found it a little complicated at first, but staff were very patient and explained in detail if I had questions.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“It is useful to have access to information online.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Regular contact made to feel that I was doing something worthwhile.”</td>
<td></td>
</tr>
<tr>
<td>After the study - study results</td>
<td>“I would love follow-up information as to how I have helped with research on the results have been analysed/published (follow up letter/email or such).”</td>
<td>“Nothing. I had no information or follow up - Some communication about what the research was about.”</td>
</tr>
<tr>
<td></td>
<td>“I definitely would like to find out the final results of the research and assume that the person in charge of the programme will be sending out copies of the final report. I prefer to receive a paper copy by post if possible.”</td>
<td>“I would like to have been able to know the results of the research.......I would like to take part again if relevant.”</td>
</tr>
</tbody>
</table>

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4.3 Issues affecting participant experience of research

Survey respondents raised a range of issues impacting their experience of participating in health research in the open text response. Frequency of mentions of most commonly occurring themes in the open text responses is presented in the chart on page 15.

% of the text responses

- Information: 38.8%
- Research Staff: 33.5%
- Motivation: 13.8%
- Research Intervention: 9.7%
- Organisation: 3.4%

‘Information’ is most likely the highest occurring theme due to the question specifically mentioning information being asked before the open text question.

Research Staff

The proportion of instances where NHS research professionals were mentioned (approx. 39% of spontaneous free text responses) reinforces the key role of research staff in shaping participant experience. The significant majority of such comments were positive and key staff qualities referred to were:

- Friendliness
- Professionalism
- Knowledge
- Approachability
- Helpfulness
- Respectfulness
- Informativeness
- Responsiveness
- Appreciativeness
All these elements are likely to have an important impact on participants having a sense of:

- Trust and confidence
- Purpose
- Being valued
- Feeling part of and contributing to something valuable to many (a greater whole)
- Social contact
- Commitment despite sometimes difficult and uncomfortable situations.

Staff who build trust with participants are pivotal to a good overall experience and support, good information, organisation and create the 'tone' of the study as well as that of the environment where participant visits are required. Feeling valued seems to be central to participant experience.

"The whole experience made me feel that I am not alone in the experiences and feelings I have caring for my husband with Alzheimer’s. The staff were so friendly, knowledgeable and supportive that I was very sorry when the study came to an end - actually six months earlier than expected."

"I have enjoyed taking part in this research. All the staff I have met have been very caring and considerate. They have treated me with kindness and haven’t tried to hurry me when my disabilities have slowed me down.

"The lady in charge of this study is so lovely and easy to talk to (as are all the people connected to this study) that you feel like you can approach them for any problems or information."

"Most of all the friendliness of absolutely everyone there was amazing. It made you feel like they really care and I cannot express the gratitude I feel and how much it benefits your health to think that someone cares. p.s you’re good at taking blood, it didn’t hurt at all!"

"They are so good and always make me feel involved by communicating so well."

"All staff were knowledgeable, courteous and friendly. I was praised, reassured and encouraged in turn."

"Also everyone connected to the trial have always been kind, helpful and although very busy people have always had time for me. I class them all as my friends."

"You wasn’t a number and you made friends."

"I felt a lot of support through an already difficult situation. There was a lot of appreciation as well."
4.4 Participant motivation and benefits

Understanding why participants take part in research and how they feel they benefit from is important in informing strategies to open up research to more and different participants. Respondents to the 2018-19 survey commented both on why they took part in the first place, and what motivated their continued engagement. As with previous surveys, common participant motivations were:

- Altruism

  "I have enjoyed being in trials as this will help other people."
  "I do feel I am contributing to improved care for future generations."
  "If it helps someone else, it is worthwhile"
  "Delighted to participate and hope it is of use."
  "It has not caused me any inconvenience & knowing it can help others is a bonus. I also view it as ‘giving back’ to the NHS (a minuscule amount compared to how much the NHS has given me)."
  "Sometimes you don’t get to hear the outcome, but feel it’s important to participate."
  "Mum felt happy because one day it may help someone."

- Improved monitoring and care of their own condition

  "I appreciated the more regular chance to check in with my oncologists."
  "Went on trial as more opportunity to see specialists and raise any concerns."
  "With the close monitoring/treatment from everyone, I now feel a lot healthier!"
  "It was extremely helpful in monitoring my own condition - enabled me to talk to my own health professional about it - but also gave me confidence that the drugs we are prescribed are being rigorously monitored too."
  "I felt that my condition was being monitored and treated properly during my time on the study."
• Possibility of improving a personal medical condition

“I believe that without the trial I would not have responded to my treatment as well.”

“After much thought, discussion with my family and study doctor I decided that if on the study medication it could very much benefit me and if successful could help many patients in the future.”

“Apart from the fact that the drug being trialed has prolonged my life. It has also made me feel that I am doing something worthwhile.”

“So far there has been little or no improvement in the condition. While I appreciate a ’‘Study’’ I really want improvement.”

“I felt being part of the research helped my case maybe got treatment i would not have had otherwise.”

• Improved understanding about a personal condition

“The process has made me much more aware of my condition and that advice and care was immediately available.”

“The experience was useful to me with regards to understanding the condition that I have.”

“Helps to get more information about your own condition. It is good to give something to the NHS.”

“I believe by taking part in research gives not only medical professionals but also patients a better understanding of their conditions and how best to improve treatment.”

What drives participants to be part of studies, whether altruism, more intensive monitoring of a condition or simply curiosity or a combination of things, understanding participant motivation, and demonstrating appreciation of it is also key to underpinning ongoing engagement in the study. It may also make the difference to how participants communicate
about research to friends and family and whether they would consider joining another study in future.

**Research Intervention**

The most common issues raised amongst mentions of the research intervention (n = 386) were:

1) impacts on health (whether taking part helps the participant’s health or not)
2) intervention design (what taking part involves for the participant)
3) unpleasant side effects or implications of the intervention

The research intervention can understandably be a key determinant on how positive or negative a participant’s experience is. However, the effect of the research intervention combined with other aspects of the participant’s experience to shape their overall impression of taking part. For example, while adverse reaction to a drug might be a poor aspect of the participant experience, respondent comments show this can be countered by excellent and timely care by clinical research staff. On the other hand, studies that involve seemingly simpler interventions like completing a questionnaire can become a poor experience if there is limited or low quality contact from the research staff.

The role of the research intervention in shaping participant experience highlights why it is so important to involve patients and the public in the earliest stages of the design of every study. Such involvement helps ensure that far as possible, any factors that may contribute to an adverse participant experience are identified and mitigated.

**Study Organisation and Environment**

Around 4% of open text responses referred to the logistics of taking part in the study. Commonly raised issues across those responses were:

- Parking
- Payment of expenses
- Site location proximity/convenience
- Adjustment for general health and disability issues of individual participants
- Waiting time in clinic and between clinics
- Appointment/procedure frequency and length of time
- Flexibility and recognition of time priorities of individual patients
- Ambience of onsite environment - e.g. availability of refreshments, noisy/quiet, busy/calm, attitude of others in the general environment.

Making it easy to participate is important to ensure there is greater equity in access to health research and issues like the above must be considered throughout site selection and study design and set-up.
“Comfortable environment, time to think and discuss throughout the questionnaire.”

“Appointment held in a cramped office. The researcher was distracted (and so was I) by a telephone call and someone entering the room.”

“Recommended eye drops to doctors surgery who refused to prescribe them. Had to pay £17.10 at chemist. As an OAP this is very expensive on a limited income. Would be helpful if the X Study used their own prescription.”

“May be easier if interview could take place outside normal working hours, difficult to take part if working full time.”

“Some tea and coffee would have been nice.”
5. Understanding negative survey responses

In order to promote access to health research to more and different individuals, it is important to make the process of taking part as positive as possible, including by finding out about what hasn’t worked well for participants and improving it. However, research participants who have had negative experiences of taking part in health research are likely to be underrepresented in this survey since these participants may have:

- Withdrawn from studies at an early stage and missed the opportunity to complete the survey (many local surveys were only made available in clinical waiting areas and therefore to study participants)
- Chosen not to complete the survey (e.g. too stressed, irritated by experience, not enough time).

As we don’t have feedback from these groups, one way we can try and understand some of their experiences is to look at the negative responses of those who did complete the survey. While this may not highlight all the reasons why people don’t take part in studies or chose to withdraw, it may show some areas where improvements can be made that could result in some individuals being more likely to take part in future.

Of those who indicated they disagree or strongly disagree that they had a good experience of research (2.5% of respondents, n=212) and provided a comment (n=89) the following themes emerged.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Respondent comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schedule and burden</td>
<td>“I feel I have participated long enough and wish to come off the trial.”</td>
</tr>
<tr>
<td></td>
<td>“I was not told the sponsor would only be covering £50/day expenses which is barely 1/4 of what it is costing me in train fares and occasionally have had to pay for overnight stays in hotel.”</td>
</tr>
<tr>
<td></td>
<td>“The only &quot;Fly in the Ointment&quot; was car parking - It was a nightmare (&amp; expensive!).”</td>
</tr>
<tr>
<td>Level and quality of</td>
<td>“Following discharge, post operatively it was difficult to contact medical professionals when problems arose. Lack of post op support”</td>
</tr>
<tr>
<td>information/communication/</td>
<td>“I attended an appointment to see a nurse. On arrival I found I was in a research project. I could have refused but the Consultant was focused on the project and not why I was there. My condition was not top of the agenda and I felt the consultant was all about the research”</td>
</tr>
<tr>
<td>contact</td>
<td>“Rushed and unclear. The purpose of the study wasn’t fully explained and the question booklets provided were confusing and poorly put together”.</td>
</tr>
</tbody>
</table>
Unpleasant or inconvenient process/intervention/side effects

“The research study has not benefited me. Felt more vulnerable and unprotected. In my opinion the people running the studies should put the patients' health and safety first.” (Mental Health)

“I suffered side-effects and a fungal infection which made me quite ill”

“I didn't realise with the patches what problems I would encounter with breast tissue growth, and then never getting rid of it total.”

“The group that I was part of was more for couples, not people living alone. The study focussed a lot on feelings and emotions which was difficult. I couldn't take part in some activities due to sight problems but the staff were helpful and approachable” (Mental Health).

Organisation/environment

“Clinic appointment changed twice without notice, save a telephone call-helpful staff and follow through.”

“Sometimes there are problems with the ECG machine and I am left waiting for a while in a cold room with a nurse, a researcher and a doctor who are trying to sort it out. Sometimes it takes a while for the expenses to go through. They must realise we are on benefits and need the money.”

“3 hours travel, being in hospital all day a minimum of 3 times a week, sitting for hours waiting for appointments, blood tests results or a bed to be free is gruelling. Side effects are painful and make breathing, eating and sleeping difficult.”

The above table illustrates some important areas of awareness for the research community. It is possible that some of these negative experiences might have been avoided through:

- Study design (particularly interventions) being more patient centred
- Recruitment strategy more considered from a patient point of view
- Site level checks and reviews of participant pathway to ensure it is patient friendly (can be checked with site patient walk throughs - see recommendations)
- Patient centred attitude at site level with follow through
- Adequate, timely and reliable communications

Some negative experiences are entirely independent of these factors, for example, changes in circumstances, unexpected clinical reactions etc. but these still need bearing in mind when considering approaches to study design, site organisation and recruitment as well as good risk management approaches.

**A note on Research Governance:** There are also some more worrying comments which suggest poor or negligent compliance with Research Governance practice. Whilst these are very few they are never-the-less critical and if accurate, should not happen at all if proper Research Governance procedures are followed.
For example:

“I opted for medical management of an ectopic pregnancy, and was told I had to be part of the trial or go to a different hospital. I disagree with this and strongly feel I should have had the option not to be in the trial and still be treated at XX. The trial leaflet clearly states that choosing not to be in the trial would not affect my treatment.”

“I felt quite pressurised to take part and the researcher who was recruiting to the study was hovering around me. I expressed ambivalence about taking part because I needed to get to work but I didn't feel that they registered this. I felt that my clinical care was organised around making sure that I took part in the study.”
6. Recommendations for improving participant experience in NIHR supported studies

Based on the results of the Research Participant Experience Study, the following recommendations are made for each stage of the study life cycle, to improve participant experience.

<table>
<thead>
<tr>
<th>Stage of Study life cycle</th>
<th>Patient Experience Theme to consider</th>
<th>Responsible/Guiding/Influencing bodies</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study design</td>
<td>• Information • Research Intervention • Organisation</td>
<td>• Study team • NIHR Research Design Service • NIHR INVOLVE</td>
<td>• Early patient involvement to help optimise patient friendliness of the study design and intervention.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Ensure participant information needs (progress updates/feedback/practical issues) are mapped into the study plan and approach at the beginning.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Plan to provide study results to participants at the end of the study as a matter of courtesy.</td>
</tr>
<tr>
<td>Study approval</td>
<td>• Motivation: • Information • Research Intervention</td>
<td>• HRA, MHRA • Study team</td>
<td>• Patient information sheet and consent form easy to understand (plain English) and engaging. Ideally has patient input as to how written.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Feedback results of this survey to Ethics Committees.</td>
</tr>
<tr>
<td>Study funding</td>
<td>• Research Intervention • Organisation and environment</td>
<td>• Study team • NIHR Funding panels • Core funders</td>
<td>• Ensure sufficient resource provision to cover participant parking, transport and expenses.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Ensure sufficient budget for taking study nearer to potential participants where appropriate.</td>
</tr>
<tr>
<td>Site identification and selection</td>
<td>• Research Staff • Information • Organisation</td>
<td>• Study team • NIHR CRN Site Identification Service • NIHR CRN Specialties • NIHR LCRN</td>
<td>• Feedback results of this survey to CRN Specialties and Partner Organisations via LCRNs.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Review and update CRN Study Support Service guidance where appropriate.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Rationalise site locations to balance</td>
</tr>
<tr>
<td>Site set up</td>
<td>• Research Staff</td>
<td>• NIHR LCRN Site Team</td>
<td>• Update the existing site and study team checklist based on themes in this report (see appendix).</td>
</tr>
<tr>
<td>• Information</td>
<td>• Patient Research Ambassadors</td>
<td>• ‘Walk throughs’ with patients before opening site</td>
<td></td>
</tr>
<tr>
<td>• Research Intervention</td>
<td></td>
<td>• Utilise checklist based on this report</td>
<td></td>
</tr>
<tr>
<td>• Organisation</td>
<td></td>
<td>• Make this report available to Patient Research Ambassadors, hospital volunteers, local PPI groups, site teams.</td>
<td></td>
</tr>
<tr>
<td>• Environment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recruitment</td>
<td>• Motivation</td>
<td>• Site team</td>
<td>• Familiarise recruiting staff with the themes from this report. Utilise quick reference checklist based on this report.</td>
</tr>
<tr>
<td>• Research Staff</td>
<td>• Patient Research Ambassadors</td>
<td></td>
<td>• Revise GCP to assure patient centred approaches</td>
</tr>
<tr>
<td>• Information</td>
<td>• NIHR LCRN</td>
<td></td>
<td>• Ensure patients are absolutely clear that the choice they are being given concerns a research study (not just a different treatment) and what follow up they will get.</td>
</tr>
<tr>
<td>• Research Intervention</td>
<td>• Site based staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Organisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Environment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undertaking research</td>
<td>• Motivation</td>
<td>• Site team</td>
<td>• On site patient ‘walkthroughs’ will often help identify problems in the patient pathway with the study especially when checked against the themes.</td>
</tr>
<tr>
<td>• Research Staff</td>
<td>• Patient Research Ambassadors</td>
<td></td>
<td>• Information at critical times such as updates and test results is very important in keeping patients engaged.</td>
</tr>
<tr>
<td>• Information</td>
<td></td>
<td></td>
<td>• Continue to check issues affecting patient time and access to both site and processes.</td>
</tr>
<tr>
<td>• Research Intervention</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Organisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Environment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study closure</td>
<td>• Motivation:</td>
<td>• Study team</td>
<td>• Provide study results to former</td>
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</tbody>
</table>
7. Recommendations for future development of the Research Participant Experience Survey

It is important that every participant in health research is offered a chance to feedback on their experience. In 2018-19, only around 1% of participants in NIHR supported studies took part in the Research Participant Experience Survey. The current approach to conducting the survey has a number of constraints which limit the extent to which the reach of the survey can be increased. These include:

- **Resource intensiveness**: the methods of collecting, manually inputting and analysing data across 15 separate local clinical research networks means that conducting the survey requires a substantial amount of resource from LCRN PPIE staff and other colleagues. As respondent numbers increase, so does the resource required to manage the survey.
- **Local expertise**: the design and delivery of the survey by local leads who may not have expertise in questionnaire development contributes to issues with data quality. As respondent numbers increase, so do data quality issues. In 2018-19, data from 159 respondents had to be excluded from analysis due to issues with data quality.

Additionally, the fact that the survey respondents are not, in most areas, linked to study and sites limits the value of the responses collected. Not having the link to study and site means that good practice cannot be located and highlighted but also that LCRNs and the CRN CC national PPIE cannot target support with involvement as we don’t know where it could add most value.

To help fulfil the ambition of every participant in an NIHR supported study being offered the chance to give feedback about the study, the CRN Coordinating Centre is convening a national advisory group to provide expert direction in the development of an updated approach to implementation of PRES, from 2020-21 onwards. The aim is to develop an approach which:

- Can link survey results to studies and sites- and NIHR specialities
- Increases reach of the survey without increasing the resource burden on LCRNs
- Improves the quality of data collected by the survey
- Enables and encourages access to and use of the survey results by all members of the health research community, including Principal Investigators and research teams, commissioners, funding panels, research advisors, actively involved patients, site delivery teams and oversight bodies.
The development of such an approach would contribute significantly to a transparent and evidenced patient centred research culture in the NIHR.
Appendix 1: LCRN Data Variations

Data collection methods

In addition to the above there have been some variations in the data collection methods between LCRNs as below:

- Paper questionnaire:
  - Data collection in clinic among those who are already participating in research,
  - Questionnaire including the prepaid return envelope has been posted to those who has completed the research study

- Online survey:
  - Survey Monkey,
  - Google form

Some LCRNs have involved their Patient Research Ambassadors to assist in completion of the survey for participants.

Settings

LCRNs had different approaches to collect data from their NHS trusts and partner organisations. Some LCRNs only focused on smaller trusts and partner organisation and some approaches all partner organisations in their local area. In addition some data have been collected at Primary Care settings.
Appendix 2: Optimising Research Participant Experience Checklist

This checklist is based on feedback from 8,507 research participants during 2018/19. It is designed to be a helpful resource that can apply to a range of types of study and site environments. It could help inform the focus of patient and public involvement in research design and delivery.

The top tips can be used as a checklist in many situations by research teams, site teams and supporting staff. For example:

- Study design
- Patient Information
- Budget planning
- Study roll out
- Site selection
- Site set up
- Research staff training
- Recruitment strategy
- Study management
- Site monitoring
- Study closure

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Insight</th>
<th>We found that:</th>
</tr>
</thead>
</table>
| Ensure site **research staff** are supported and have sufficient time allocated to build excellent working relationships with patients taking part in the study. | The relationship with research staff is absolutely key to the experience of study participants. | What was most appreciated was staff’s:  
  - Friendliness  
  - Professionalism  
  - Knowledge  
  - Approachability  
  - Helpfulness  
  - Respectfulness  
  - Informativeness  
  - Responsiveness  
  - Appreciativeness |
| Ensure the right **information** is available in the right place at the right time as participants proceed through the study. | Having good timely information is important to people feeling engaged in and valued as participants in a study. Consider methods e.g.  
  - Verbal  
  - Written  
  - Online | The types of information important to participants were:  
  - Quality of **pre-consent information** (written and verbal)  
  - Practical timely information about the **process**: appointments, what to expect, where to be, when and how.  
  - Timely updates about **progress of study**  
  - General **information about the health condition** |
<table>
<thead>
<tr>
<th>Motivation</th>
<th>People participate in studies for a range of individual reasons. Understanding a person’s motivation for participating can help you to help them feel fully engaged.</th>
<th>In order of frequency of mentions in participant feedback, motivations were:</th>
</tr>
</thead>
</table>
| Actively appreciate the **motivation** of patients for joining a study and be prepared to explain health issues. | People’s time, access, costs, etc. are important to them and should be respected. **Walkthroughs** by patient representatives before starting site recruitment proper, help identify difficulties sooner rather than later. | - Altruism  
- Medical monitoring  
- Improving condition  
- Learning about condition  
- Interest |
| Carefully consider participant’s pathway through consenting and starting a study to subsequent study ‘visits’ in the way the study and sites are **organised** | The general environment will affect how a participant feels about the study. | This includes: |
| Carefully consider the effects of the **environment** participants will be moving through | | - Waiting time in clinic  
- Appointment coordination frequency and length of time (Design)  
- Expenses and how and when incurred and paid  
- Burden of **travel and parking**  
- Flexibility of **appointment times**  
- Location **proximity/convenience**  
- **Disabled access** (e.g. visual impairment, wheelchair access etc)  
- Ambience of onsite environment - e.g availability of refreshments, noisy/quiet, busy/calm, and attitude of others in the general environment is important |