NHS
National Institute for Health Research

Clinical Research Network Coordinating Centre

Report of the Patient Research Experience Survey 2016/17

National data collection, analysis and recommendations

July 2017

Mana Golsorkhi
Roger Steel

V 2.0

Delivering research to
make patients, and the NHS, better

What this Report is about?

This report is about the results of a survey of patients about their experience of research that took place in 2016/17. The information was collected through a number of local surveys carried out by a number of Local Clinical Research Networks (LCRNs) across the England. These used the same or very similar core questions so that a national analysis would be possible. The report shows the result of the analysis and makes recommendations.

It follows an initial report of a pilot national collection of patient experience survey data during 2015/16[1].

[1] Golsorkhi, M., Steel, R. 2016. 'Learning from Patient Experience of Participating in Research', NIHR Clinical Research Network

Contents

Section Heading		Page
1.	Context	4
2.	Scope of the report	5
3.	Summary of results	6
4.	What feedback was collected and how	8
5.	Approach	10
6.	Feedback and data analysis	11
7.	Comparison between 2015/16 pilot and 2016/17 results	12
8.	Understanding lower scoring responses	13
9.	Recurrent themes	15
10.	Commentary on themes from patient experience and recommendations	21
11.	Conclusion	24
	Appendix 1: LCRN Data Variations	25
	Appendix 2: Local Clinical Research Network Reports	28

1.Context

The National Institute for Health Research (NIHR) Clinical Research Network (CRN) has developed an approach to understand the experience of patients participating in health research. Last year we piloted the first national data collection through our Clinical Research Network infrastructure. This made way for a year on year commitment to assure good levels of patient research experience through regular patient feedback. All parts of the CRN are expected to gather data annually although the targeting of these surveys may differ and evolve in overall focus according to local information needs. Based on previous experience of piloting this work, during the year 2016/17 we identified some core questions applicable to all CRN surveys so that a national collection and analysis could be made. This report is about the analysis of the core national questions.

The ultimate aim of this work is to develop a helpful and supportive 'service improvement' programme based on patient experience of research within the CRN both locally and nationally. As the data shows later in this report, there is much we can continue to learn from what patients find important through their feedback, whether expressed negatively or positively. The purpose is to ensure that we continue to optimise patient research experience through the aspects of the business of delivering research that we undertake in the Network.

However, although the remit of the NIHR Clinical Research Network is on research delivery alone, we recognise the importance of patient orientation in the earlier stages of research development since this influences the experience of participants later. For this reason we recognise the value of making patient research experience feedback available to the wider clinical research infrastructure in this country.

Participating LCRNs and their NHS Partner organisations are to be thanked for excellent work in designing and deploying surveys, and gathering and uploading data both for their own local purposes and also for including the nationally requested questions as part of their survey. This is no mean feat and takes considerable time and planning. Most importantly, the patients and public who completed the questionnaires are to be thanked for their time and valuable feedback.

Thanks are also due to Robert West, Professor of Biostatistics, University of Leeds who is a chartered statistician, mathematician and scientist and who kindly provided expert guidance on our approaches to the data.

2. Scope of the Report

The report covers data collected (September 2016-April 2017) from patient satisfaction surveys that were given out to people already participating in research studies or who had recently completed a study through our network partners in the NHS. It focuses on four core questions (described in detail later in the report) and does not include personally identifiable data.

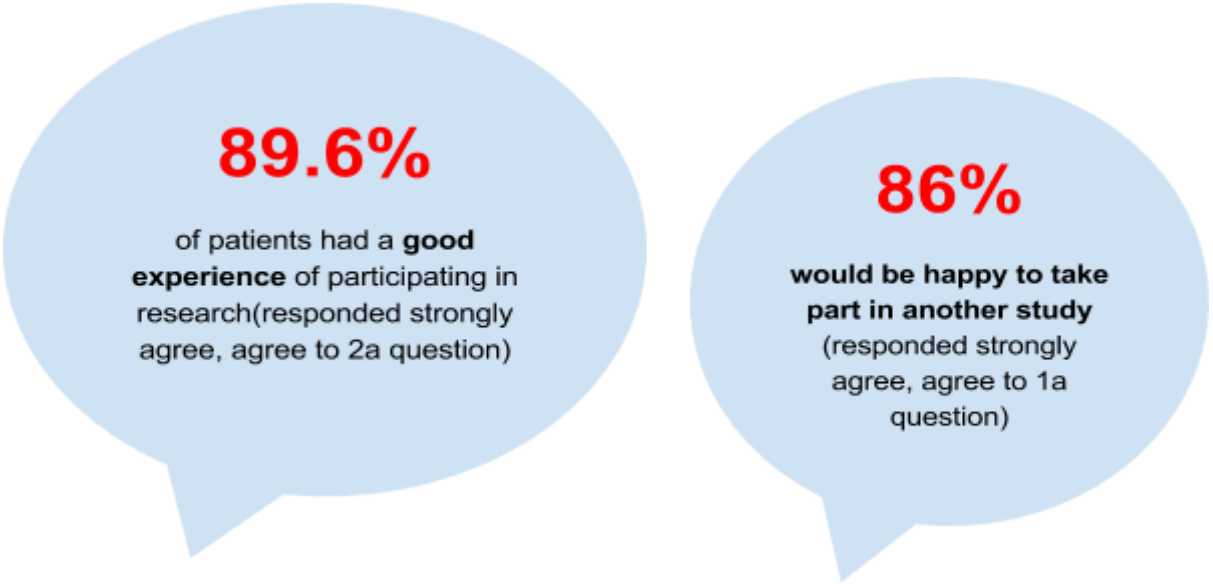
The data therefore does not include feedback from people approached about participating but who decided ***not*** to take part. This would require a different approach altogether. The summary results to follow look very positive, and most likely there is a very good level of satisfaction with patient experience of research. However, it should be remembered that the sample is taken mainly from people already committed to participating in studies, and does not capture those who may have pulled out of studies because of poor experience. Without being able to measure this attrition, which may or may not be significant, it is difficult to be 100% confident that the full picture has been captured.

The CRN recognises the critical importance of gathering information about whether patients have been approached about research relevant to them in the first place. Again this would require a different approach. However, we hope in time the organisation, partnerships and systems needed to do this will become more available in the future.

3. Summary of results

The number of respondents in the national collection was **n = 3,320**.

This survey showed that:



(The calculations used to reach these percentages included blank responses in the data fields.)

Key themes in the feedback in order of frequency of occurrence in comments:

"Research Staff: By far the highest occurrence of mentions in the freetext fields were about the friendliness, professionalism, knowledge, approachability, helpfulness, and respectfulness of staff. This strong appreciation of staff was also expressed frequently in comments of those who had indicated that they were unlikely to take part in another study. Good working relationships with staff are clearly key to good patient experience.

"Motivation: Free Text responses revealed much about the importance of motivation which was mentioned in many comments. In order of frequency of occurrence typically these reasons were:

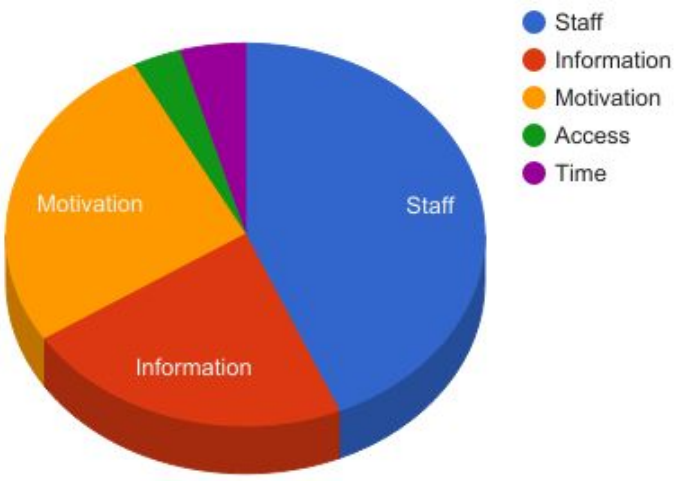
- Altruism and improving medical knowledge
- Possibility of improving own health condition
- Better medical monitoring
- Learning about a medical condition
- General interest in the process of research

"Information: Mentioned in a good number of comments was having information in the right place at the right time showing its importance to people in feeling engaged with the study patients were participating in. This included being told about results.

"Time: This was mentioned in comments showing that time being respected is important issue for a number of patients when participating in studies.

“Access: There were also a scattered range of comments generally about access and these tended to be about timing, location, travel, parking, and disability.

Not all respondents to the survey made comments. However, the following diagram provides a general idea of the ***distribution*** of mentions among the themes:



4. What feedback was collected and how

Each participating LCRN designed their own questionnaire and this enabled an important local focus (Appendix 1). Some LCRNs provided opportunities to complete questionnaires electronically online but it seems that the majority of patients preferred responding to printed surveys. There were four questions core questions that required as standard in all the LCRN surveys to enable the national data collection in this report:

Required Questions 2016/17			
	Type of Question	**Question/Statement**	**Format/options**
1a	5pt Rating scale	I would be happy to take part in another research study.	Rate on the scale, where 1=Strongly disagree and 5=Strongly agree
1b	Freetext	Use this space to tell us more about your answer.	Text box
2a	5pt Rating Scale	I had a good experience of taking part in the research study.	Rate on the scale, where 1=Strongly disagree and 5=Strongly agree
2b	Freetext	Use this space to tell us more about your answer.	Text box

In practice there were some slight variations in the way some LCRNs asked the freetext questions. We also recognised that how these questions appeared in the context of each of the local surveys may have also had an effect on how they were answered. The approach to the national analysis however took this into account, and was able to draw useful conclusions by cross referencing and coding for key themes.

All additional information was stripped out of the raw data collected nationally except for the identity of the LCRN providing each data set. This latter data was for administrative purposes only. It was expected that more detailed analysis would be made for local service improvement and communications purposes by each LCRN using their full data sets.

Not all LCRNs were able to provide their data in time for the national data collection deadline, and in some cases the required national questions were not used.

Overall number of responses through the seven LCRNs were:

LCRN	No. of responses
Kent, Surrey and Sussex	526
North East and North Cumbria	384
North West London	4
South West Peninsula	1,486
Thames Valley and South Midlands	34
West Midlands	585
West of England	301
Total	**3,320**

5. Approach

Although the breadth of data gathered for 2016/17 pilot was narrower than that during the 2015/16 pilot, we took a similar approach. First we filtered scores from the preference scales to create a baseline quantitative analysis. Then, again using filters we looked across for corresponding comments made in the freetext fields in order to identify themes. We later cross-checked these themes by applying coding and keyword searches to monitor occurrence and identify any other themes to be taken into consideration.

Although the dataset is narrower in this 2016/17 national data collection than previously, the core questions chosen were sufficiently corresponded to be able to make a broad comparison.

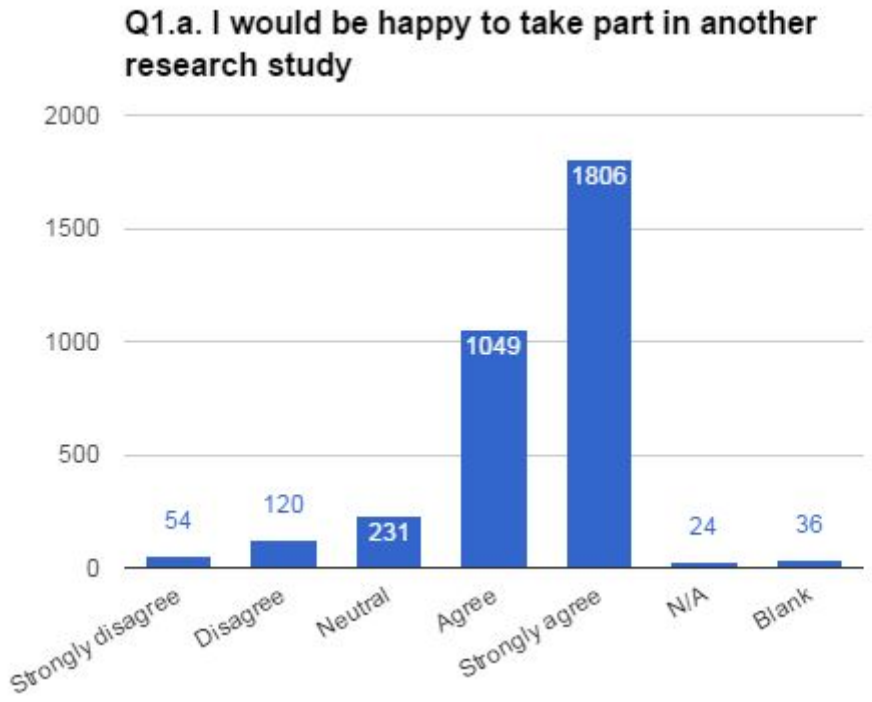
However, it is important to note the very significant difference in the quantity of data collected:

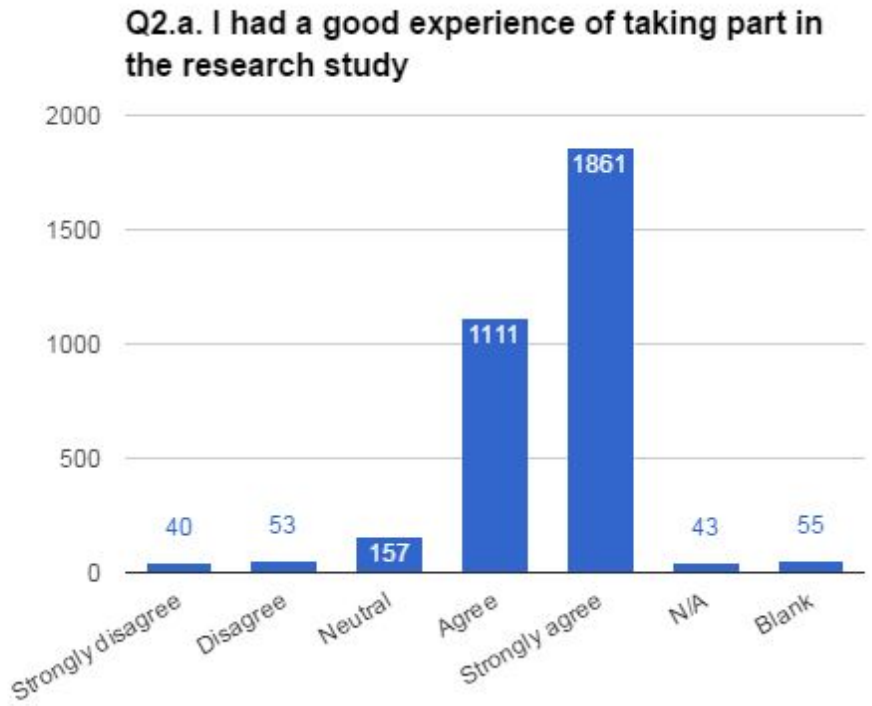
2015/16 pilot: n = 597

2016/17: n = 3,320

6. Feedback and data analysis

The results of the quantitative questions asked in the 2016/17 survey are presented in the following graphs:





7. Comparison between 2015/16 and 2016/17 results

Given the difference between the size of the data sets from two consecutive years, we thought it might be insightful to make a comparison. Although we did not ask the questions exactly the same way in these two surveys we used equivalent questions for the comparison:

2015/16 pilot **n = 597**	Would you consider taking part in another research study if you had the opportunity? (5 point scale/ **definitely**)	Overall how would you rate your experience of taking part in research? (10 point scale/**excellent**)
	73%	**58%**

2016/17 survey **n = 3,320**	I would be happy to take part in another research study. (5 point scale/ **agree + strongly agree)**	I had a good experience of taking part in the research Study. (5 point scale/ **strongly agree)**
	86%	**56.1%**

These summary figures show a similar ***order*** of % outcome and gives additional confidence that we are capturing a general level of patient research experience in studies at this period of time. However, due to the variation in the way the questions are structured and contextualised in the two surveys it would be unsafe to draw more specific conclusions from the comparison.

It should also be noted that the themes that emerged from free text comments are very similar between the two surveys. The main difference in 2016/17 survey is that ‘location’ was brought into a more general category about access to research.

8. Understanding lower scoring responses.

As with the earlier pilot survey it was found that negative scale scores (disagree/strongly disagree) and comments were very much a minority. This was however a good reason to give the comments associated with them close attention. Of those who indicated they would not be happy to take part in another study (5.2%) (n = 174) recurrent reasons, where given, were themed as:

Area	**Sample comments**
General health/Ageing	'My health doesn't allow me to do it' 'I worry too much'. '95 years old, have appreciated the opportunity but do not think I could withstand another'.
Travel/ access/venue (including parking)	'Would have preferred X Hospital as unable to park at the Y Hospital (for the research)'. '30 mile round trip and no pass for parking'. 'Access - entrance door is very restrictive for poor mobility'. 'Difficult to attend due to distance' 'No it costs me time and loss of earnings'
Time and waiting	'The waiting time between the investigations is too long. Each visit takes 4-6 hours'. 'Retired but don't have time for another (study)'
Unpleasant side effects or bad reaction first time	'Taken out or research as the Herceptin upset my heart's blood flow' 'There would have been more interest if I had been able to take the prescribed drug but as it did not agree with me I became only a placebo patient'.
Did not like clinical procedure	'I hate needles' 'Did not enjoy using pessary'. 'Too deep in my ear' 'Possible for the pod in the mask to be a bit softer as it was hard on my face when the mask slipped in bed.'

	'The research book is too big and takes too many hours to complete. Many of the questions are the same just framed differently. They are also depressing - how many times do we have to be asked 'Is my life worthless?'
Information/communication	'I didn't fully realise, in the first study, how long my needed surgery would be delayed if, as was the case, the drug was ineffective (or it could just as easily been a placebo)'. 'In the second study I didn't understand that the follow ups continue for a (further period)'. 'Didn't realise that (obtaining) travel insurance was not possible during a drugs trial'. 'Never felt involved or kept up to date. I am only seen once a year.'

The table above illustrates some important learning points. Probably a significant portion of these negative experiences might have been avoided through either the study design being more patient friendly, better consideration of site distribution or individual site organisation being more patient friendly. In some cases of course the reasons given are personal and entirely independent of these factors but still need bearing in mind when considering approaches to recruitment.

The themes identified in the above table echo most themes identified across the entire response to the questions/statements in terms of **what is important to patients**. This is evident from both positive and negative feedback since the comments left were largely spontaneous.

9. Recurrent themes

Research Staff: The instances where NHS research professionals were mentioned was **very high**. The appreciation of staff was expressed frequently. These comments occurred independent of whether the respondent had indicated that they were likely or unlikely to take part in another study.

In this large sample there were only three negative comments about staff found in the entire data set and two of these seemed to be about non research staff:

'Initial nurse a bit 'iffy''

'I would be happy to take part in another study, so long as it's not with the lady that we currently see. ** I don't mean that researcher that gave us the form, I mean the lady I/we see at our appointments'.

'Got the impression from the research team that I wasn't the type of patient they wanted.'

Much suggests that the interaction with medical professionals through a research study was more satisfactory than in standard care. What was appreciated was the experience of staff's:

- Friendliness
- Professionalism
- Knowledge
- Approachability
- Helpfulness
- Respectfulness

This list strongly reflects the feedback from the 2015/16 pilot survey. Here is a very small sample 519 comments that were explicitly appreciative of staff:

'Excellent medical staff. Nothing too much trouble for them'.

'Staff excellent made you feel comfortable'

'I know team members well and that helps build confidence'.

'I felt comfortable, not judged and safe'

'This study and former studies I have participated in make me feel I have not been shelved plus the study nurses have been extremely present throughout.'

Motivation: Freetext responses revealed much about the motivation of people. (Comments, n=315). In order of frequency of occurrence typically these reasons were

- **Altruism and improving medical knowledge.** This was mentioned in comments frequently and is clearly a **strong motivator:**

'Makes you feel you are doing something positive.'

'Over the last 10 years I have benefited greatly from NHS treatments. By doing this, I hope that I can give something back.'

'I wouldn't say that I had a good experience. Research is necessary for improvement. I wouldn't say that I had a bad experience either.'

'The researchers made me feel hopeful not only for myself but for others that the studies may benefit in the future.'

'I liked being useful to help in mental health research'

- **Possibility of improving a personal medical condition:** This appeared to be an important aspect of being involved in research for a **high** number of patients comments:

'If the research helps me I would be happy to take part.'

'I took part in the study to improve my condition and the whole experience has been so positive. I would highly recommend it to others.'

'Helped with my weight problem.'

- **Better medical monitoring:** A good number of comments referred to the extra medical monitoring patients had in the studies in which they participated.

'I feel that I am being given greater attention because I am part of the trial.'

'I feel I received a lot of benefit regarding my individual health concern i.e more frequent check ups and follow ups.'

'3 monthly checks. At the end of the phone if I have any questions.'

'Something was discovered which was in fact minor but could have been worse later in life if I had not been on the programme.'

'Things missed previously were picked up.'

- **Learning about a personal condition.** This was mentioned specifically a number of times in comments so could be regarded as potentially **significant as a motivator** for patients:

'(The nurse) was very helpful and very friendly and gave out very good advice.'

'Personally - the research I took part in has given me a clearer insight into my illness - and new tools with which to fight it.'

'Taking part in the study is beneficial in terms of better understanding my condition.'

'Actually seeing pictures and being able to ask questions on what I saw was a plus point.'

'It was interesting to find out how your own blood can help to heal an ulcer.'

- **Interest in the research process.** There were a small number of comments about a general interest in research, so **important for a small number of people:**

'I found the experience very interesting and would like to take part in another.'

'I've always been into research from medical to engineering improvements.'

'Interesting project that can be of benefit generally and more specifically to me'

Information: Comments (n=264) showed that having information in the right place at the right time was important to people in feeling engaged with the study they were on. This included being told about results. The feedback showed that there are different types of information important to patients during a study:

- 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
- Getting personal medical information from tests etc.
- Information about study results

A sample of direct quotes about information:

'Great email and verbal communication.'

'The studies have been clearly and thoroughly explained in advance.'

'Good professionalism, verbally everything was explained well.'

'I have been kept fully briefed at all times and all issues explained/discussed.'

'Not having taken part in a study before I was really interested about results.'

'It kept my interest information sharing is empowering.'

Time: Although not mentioned often (n=53) there were a number of comments that showed that patients' time given to a study was important to them and should be respected. This included:

- Waiting time in clinic
- Appointment/procedure frequency and length of time (Design)
- Recognition of time priorities of individual patients

Here is a range of direct comments:

'The people running the studies have been always conscious of my time and have been well organised/thoroughly professional.'

'The biggest problem that I found with the trial was the waiting time to receive the drugs after the initial tests were completed.

'With the use of a smart phone calendar it isn't difficult to programme it for prompts or reminders in order to fulfil the studies requirements.'

'Appointments were arranged well in advance and suited my timings.'

'Times were chosen to suit my lifestyle.'

Access: There were also a scattered range of comments broadly concerning access to studies and sites. These related to time, travel and parking, and disability/impairment.

- Burden of travel and parking
- Flexibility of appointment times
- Location proximity/convenience
- Disabled access (e.g. visual impairment, wheelchair access etc)

Here is a selection of direct comments concerning access:

'Might have been easier to have zoladex injections at the local surgery'

'I was able to see the researchers in my own home, much easier and relaxing'

'Just a bit concerned about the hospital parking costs which have increased'

'My only reservation is relatively lengthy bus journey'

'Easy to access and use the website. Reassuring for me'.

'Larger print for those with poor vision'

'More flexible visiting times. I used all my holiday'

Although the number of comments (n=39) related to access was small for this sample it does not make access less important. We do not know how many patients approached opted out of participating as a result of access issues, as the sample is from patients currently in or have recently completed studies. It is possible to deduce that access could be a much larger issue than is indicated in this data collection.

10. Commentary on the key themes from patient feedback and recommendations

Although this national patient research experience data collection has been the largest sample we have collected yet it should be noted that the questions, context and approaches to eliciting the data were to some extent varied, and inevitably this introduces the likelihood of biases. The themes emerging from the free text fields however echo strongly those identified in the 2015/16 pilot survey.

The themes show what is important to patients in being part of research regardless of whether these areas were part of positive or negative feedback. The themes on their own can tell us much about the different areas of the business of research that can help assure good patient experience. One of the simple ways to to describe this is by looking at the pathway a research study takes to its conclusion and identify the relevant patient themes influenced at the different stages. We can also go on to list the organisations and individuals having responsibilities, or offering services or guidance at each stage.

Stage of Study life cycle	**Patient Experience Theme**	**Responsible/Guiding/ Influencing bodies**	**Recommendations**
Study design	● Motivation ● Information ● Time ● Access	● **Study team** ● NIHR Research Design Service ● NIHR INVOLVE	● Early patient involvement to help ensure patient friendliness of the study design. ● Use checklist based on themes in this report.
Study approval	● Information ● Time ● Access	● HRA, MHRA ● **Study team**	● Patient information and consent form easy to understand and engaging. ● Feedback results of this survey to Ethic Committees.
Study funding	● Access	● Study team ● NIHR Funding panels ● Core funders	● Ensure sufficient budget to cover participant expenses such as parking and transport. ● Ensure sufficient budget for taking study nearer to participants where appropriate.
Site identification and selection	● Access	● Study team ● NIHR CRN Site Identification Service	● Feedback results of this survey to CRN Specialties. ● Review and update SSS

		• NIHR CRN Specialties • NIHR LCRN	guidance where appropriate
Site set up	• Motivation • Information • Time • Access	• NIHR LCRN • **Site Team** • Patient Research Ambassadors	• 'Walk throughs' with patients before opening site • Make this report available to Patient research Ambassadors, site teams. • Develop and use a patient experience quality checklist based on themes identified in this report
Recruitment	• Staff • Motivation • Information • Time • Access	• Patient Research Ambassadors • NIHR LCRN • Site based staff	• Familiarise recruiting staff with the themes from this report.
Undertaking research	• Staff • Information • Time • Access	• Site team • Patient Research Ambassadors	• On site patient 'walkthroughs' will often help identify problems in the patient pathway with the study especially when checked against the themes. • Information at critical times such as updates and test results is very important in keeping patients engaged. • Continue to check issues affecting patient time and access to both site and processes.
Study closure	• Information	Study team	• Share results with participants

Additional general Recommendations emerging from this report

- Celebrate and thank research staff on the front line for what they do, and how important good relations with them are to the patients who get involved in research.
- Discuss this report in NIHR PPI leadership group.
- Identify any possible amends/additions to information given as part of the CRN Study Support Service.
- Make report available to laypeople and others on LCRN Partnership Boards.

- Make summary of this report available to patients and public on research funding panels, advisory groups across the NIHR as this goes some way to providing a feedback loop.
- Where possible (given individual anonymisation), the overall results of local and national surveys should be shared with those groups of patients and carers who provided responses to questions.
- As above as well as those who facilitated the surveys at site level.

11. Conclusion

It is likely that are further potential outcomes of this work both locally and nationally. Sometimes it takes a wide range of individuals, teams, and partner organisations to recognise all the possibilities of the findings reported here and in similar local reports whether this be at a national level or a local one. This is the point of reporting it. With your help as the reader we can all make a difference to ensure patient experience of research is the best it can be so that in turn, clinical research itself can help make sure that NHS healthcare is the best it can be.

Appendix 1:

LCRN data variations

Each LCRNs has designed their local survey differently to focus on their local needs. However, LCRNs have asked the same or very similar core questions for 2016/17 survey. These were standardised nationally to enable a coherent national collection. The following shows the questions that were actually asked during 2016/17 in each of the 7 contributing local surveys:

North East & North Cumbria

1. I would be happy to take part in another research study.

Strongly disagree 1 2 3 4 5 Strongly agree

- *I would be happy to take part in another research study (comments)*

2. I had a good experience of taking part in the research study.

Strongly disagree 1 2 3 4 5 Strongly agree

- *I had a good experience of taking part in the research study (comments)*

North West London

1. I would be happy to take part in another research study.

Strongly disagree 1 2 3 4 5 Strongly agree

- *Use this space to tell us more about your answer.*

2. I had a good experience of taking part in the research study.

Strongly disagree 1 2 3 4 5 Strongly agree

- *Use this space to tell us more about your answer.*

Thames Valley and South Midlands

1. I would be happy to take part in another research study

Strongly agree, Agree, Neither agree or disagree, Disagree, Strongly disagree, N/A

- *Tell us more about your answer*

2. I had a good experience of taking part in the research study.

Strongly agree, Agree, Neither agree or disagree, Disagree, Strongly disagree N/A

- *Tell us more about your answer*

West Midlands

1. I would be happy to take part in another research study?

Strongly disagree 1 2 3 4 5 Strongly agree Not applicable

2. I had a good experience of taking part in the research study?

Strongly disagree 1 2 3 4 5 Strongly agree Not applicable

3. *Please use this space to tell us more about these answers.*

Kent, Surrey and Sussex

1. I would be happy to take part in another research study. (3= not sure)

Strongly disagree 1 2 3 4 5 Strongly agree

- *Please tell us more about your answer below*

2. I had a good experience of taking part in the research study. (3= not sure)

Strongly disagree 1 2 3 4 5 Strongly agree

- *Please tell us more about your answer below*

West of England

1. My experience of taking part in the research study is/has bee. (3=OK)

Very negative 1 2 3 4 5 Strongly positive

- *Please tell us more*

2. I would be willing to take part in another research study

Strongly disagree 1 2 3 4 5 Strongly agree

- *Please tell us more*

South West Peninsula

1. I would be happy to take part in another research study.

Agree Disagree N/A Strongly agree Strongly disagree

2. I had a good experience of taking part in the research study.

Agree Disagree N/A Strongly agree Strongly disagree

- *Please tell us anything about your research experience which was particularly good*
- *Tell us if there is anything which could have made your experience in research better.*

Appendix 2

Local Clinical Research Network Reports

In addition to providing data for the Clinical Research Network Coordinating Centres national Patient Research Experience report, LCRNs have undertaken their own local reports which contain more granular detail and breadth relevant to their day to day research delivery work.

Where shared by LCRNs these local reports of 2016/17 feedback can be found on the NIHR CRN's Patient Research Experience Framework website. If you require any assistance with accessing these reports, please contact Mana Golsorkhi Email: mana.golsorkhi@nihr.ac.uk

National Institute for Health Research

Clinical Research Network
21 Queen Street
Leeds
LS1 2TW
Tel: 0113 343 0441
Email: crnppie@nihr.ac.uk
Web: www.nihr.ac.uk