

Research Participant Survey 2017/8

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Purpose

To describe the results of a Research Participant Survey carried out Nov – Dec 2017 at both the Lister Hospital and Mount Vernon Cancer Centre.

Background

The underlying basis for the Trust’s Research Strategy is that patient care will be improved through the development of a research culture. The experience of research participants is fundamental to this. This is why feedback was sought. This local exercise is part of a national effort by the National Institute for Health Research, with regional co-ordination via CRN: Eastern.

Approach

1. During the period Nov – Dec 2017 research staff at the Lister and Mount Vernon asked if adult patients would like to complete a research participant survey.
2. The NIHR Adult Research Participant survey tool was used.
3. The data was collated internally and also sent to CRN: Eastern to contribute to the regional and national assessment – which will be reported in a separate document.

Main findings

- A total of 119 surveys were completed by the research participants with numerical data provided in Appendix 1 and the comments provided are given in Appendix 2.
- The survey design for 2017 has included some of the same questions as for 2016 and a comparison of some of these question is given below

% of research participants that either very agreed or very strongly agreed to the following statements	2016 Survey (n=100)	2017 Survey (n=119)
The study was explained to me in a way that I understood	100%	97%
I fully understood what I was consenting to	100%	99%
It was explained to me that my care would not change if I decided not to take part	98%	99%
My questions were answered in a way that I could understand	99%	97%
I was kept well informed throughout the study	98%	95%
I felt the research staff put my needs first during the study	100%	95%

- The qualitative responses were very positive around patient experience though parking remains an issue. Comments include:
“I am very happy with the care and treatment that I have received over the last few years. Both doctors and nurse have been brilliant”
“I was happy to take part in this trial/research study, in the hope that it will help others and myself”
“I have been extremely satisfied with all aspects of my care and treatment”

Actions

1. The Trust recognises and is grateful for the contribution made by patients to research and to this exercise and this is to be acknowledged publicly via the Trust’s website.
2. The Research teams are to be congratulated on their conduct of research.
3. Further analysis of the data and comments to be completed to identify ways to improve research participant experience, especially around parking.
4. The survey to be repeated in 2018/9.

Appendix 1: Results of the Survey based on the 119 responses % provided)

	Beginning	Middle	End	Don't know	Not answered	
1. At what stage of taking part in research are you?	23	62	6	8	1	
	Strongly agree	Agree	Not sure	Disagree	Strg disagree	Not answered
2. The study was explained to me in a way that I understood	67	30	1	2	0	0
3. The researcher explained all of the paperwork that I was asked to complete	71	27	1	1	0	0
4. I fully understood what I was consenting to	72	27	1	0	0	0
5. It was explained to me that my care would not change if I decided not to take part	76	23	0	1	0	1
6. My questions were answered in a way that I could understand	73	24	2	0	0	1
7. I was kept well informed throughout the study	64	31	0	2	0	3
8. I felt the research staff put my needs first during the study	71	24	0	2	0	3
	Yes	No	Not sure	Not answered		
9. Were you given a name and contact number so that you could call a member of the research team if you had a question or needed further information	94	0	4	2		
	Phone app	Email	Websites	None	Not answered	
11. Were you asked to use any of the following during the course of the research trial	4	10	4	76	6	
	PC	Laptop	Smartphone	Tablet	Other	Not applicable
12. If yes, how did you access it	4	3	4	3	0	76
	Yes	No	Don't know	Not answered		
13. Would you prefer to use digital technology rather than paper?	37	50	10	3		
	Strongly agree	Agree	Not sure	Disagree	Strg disagree	Not answered
14. I was happy with the time and date of my appointment	61	33	2	1	0	4
	Yes	No	Didn't need to	Not answered		
15. I was able to choose an alternative date for my appointment	43	3	52	3		
	Yes	No	Don't know	Not answered		
16. If it were possible to reimburse you for travel and parking costs, would that make you more willing to participate in research	26	62	9	3		
17. Getting to my appointment was easy	32	50	4	8	1	5
	Strongly agree	Agree	Not sure	Disagree	Strg disagree	Not answered
19. I know how to find out the results of the research I took part in	24	20	38	9	5	4
	Very important	Important	Don't mind	Not important	Really not ipt	Not answered
20. How important is it for you to find out the results of the research you took part in	44	38	13	2	2	3
	Strg disagree	Disagree	Not sure	Agree	Strg agree	Not answered
21. I would recommend taking part in research	9	2	0	8	77	4
22. I would be happy to take part in another research study	10	2	5	11	70	3
23. I had a good experience of taking part in the research study	8	2	5	8	71	5
	Myself	Help from friends / family	Help from staff	Other	Not answered	
25. Have you completed the questionnaire yourself	86	4	5	0	5	

Note three questions (10, 18, 24) requested a written response and these are given in Appendix 2

Appendix 2: Comments provided by the research participants. Please note that the comments are those of research participants and not necessarily of the Trust

10 Is there anything else you'd like to tell us?

I have only just been involved in this study so am at the front end of the project. I would be very happy to get further involved as this moves along
Staff were amazing, very caring and ununderstanding
All the people at the hospital involved in research very friendly and supportive
Staff are really friendly and was able to understand what I was given
All very good, cannot fault the doctors and the research team
My scoring in no way reflects the standard of nursing I received. Due to one member of staff (now left) I felt no reassurance at the beginning to what I was having to face.
During the trial I have met lots of people, doctors, nurses and admin staff. Everyone has been great.
Research staff all very professional, kind and helpful
The staff made me feel comfortable and relaxed nothing was too much for them. They had me laughing instead of panic or concerned about issues.
First part of trial was with agency nurses, and coordination wasn't quite right. It improved mostly when permanent staff took over.
Staff were very good. Voluntary staff do good work and make hospital visits more pleasant.
Privacy to fill in initial forms
I strongly feel my treatment and follow up very satisfactory, and very helpful, staff very pleasant and most helpful
Very happy with the service, it puts my mind at rest
Analyse age, lifestyle and medication tale to predict outcome over time frame - so we have expectation of recovery
The follow up and attention to my needs and concerns by the consultant undertaking the research has been disappointing.
Throughout it's been an efficient and very pleasant experience
Everyone has always been nice and friendly as well.
Very happy with the support from the research staff
Radiologist has been/is excellent
Very happy that I agreed to do the research, research staff have been excellent with me
All is fine
Extremely well organised and empathically presented care at all times
My care both by research staff has been amazing!! I can't thank them enough for their support.
The support, detailed information received at all times has been excellent.
Very professional and supportive care. Thanks.
Very helpful and empatic staff. Always willing to help
Everyone was very kind and efficient. Really went out of their way to explain and make one feel comfortable.

18 Is there anything that would make it easier for you to attend your appointment

Car park is too expensive. Makes one think different about participating in research
Weekends available or late afternoon during weekdays
No parking charges
The car park is often full, sometimes delaying appointments
Hospital transport available at most vulnerable. Then drove myself with blue badge.
Sometimes parking is a bit of an issue but most times ok
Better parking
Transport provided good, but sometimes late. Also long waiting time for transport home.
No. Everything very easy
Only live in Pinnes - so easy to get here
More car parking spaces
No thank you. Live local therefore no problem.

Shorter queue at reception. Always staff shortage
More parking spaces
Parking is often a problem
Research staff are very good, they do not get stressed if you are running late, they do not make it a problem for me
Parking
Lack of parking spaces
Difficulties travelling on two motorways. Traffic congestion. Parking at hospital good.
Parking is often congested and can entail queueing, however I managed this by allowing for the time required if appointments are later than 09.30 to 10.00am
Had a hospital appointment at that time
N/A - inpatient at the time
But car parking charges are very expensive
Free parking
Send text reminder
Parking can be a problem at certain times of the day. Parking costs can be expensive if appointment over run.

24 Please tell us more about your answers

I have been involved in previous "unique" projects within the NHS and very happy to support any further ones
I am very happy that I was taking part in this research and that I found very helpful people
I am still quite early in the research, so some questions are not easy to answer
Fantastic to be offered the research. Fantastic nurses
It is important to have the research studies to help find a cure. Having some bad side effects has made some days hard to deal with
I did not think it was my place to ask (about the results of research) but would be very interested! If you have advanced cancer and you have the option to try and improve, lengthen quality of life it is always worth it.
A more formal update on the trial might be a good thing for example a copy of trial "extracts" handed to trialists as things progress.
I noticed a difference between the research nurses. For example, with routine blood tests some times this is much more painful with some nurses compared with other nurses. It would be good to have well-trained nurses as the blood collections are so much more frequently in a trial than routine care.
Unable to answer some questions as I haven't started yet
I believe more people should take part in research otherwise things would just not progress. Happily take part to help others. My experience with this study really good, made me think and be thankful.
I have not answered some of the questions in this section as I have not finished my research studies.
The first part of the trial was a hit and miss because of temporaries
Up to other people to decide (if they want to take part in research). Depends on side effects (if I would participate in another study). No reason not to (participate in further research), but depend on why, what etc.
Have been very happy with my treatment
The results of radiotherapy are still continuing, at times unpleasant and inconvenient
My co-ordinator for this research has used her experience to explain ways to improve my lifestyle in a way that I can understand
All treatment and research worthwhile
The research nurse has been very professional and excellent in all aspects during the research period to date. I feel the research nurse needs support in being provided with a fixed room for research appointments as she is moved around on a regular basis.
I am always in favour of medical research. I have a background in bio/med research myself
Super efficient polite staff at Mount Vernon
I have nothing but the finest treatment and help during my visits.

Hope my info helps. Treatment - no problem. After effects more so. But if it cures me? Thank you you everyone involved.

Made my life more comfortable. The research staff have been so good for me and stopped me worrying about things. Excellent.

I have been extremely satisfied with all aspects of my care and treatment

I am very happy with the care and treatment that I have received over the last few years. Both doctors and nurse have been brilliant.

There is no doubt in my mind that the therapy has had a very positive impact, reducing the cancer and slowing down the process.

I strongly support research programmes and am very happy to be involved and help in any way

By being part of the study, I feel I have been checked and monitored a lot more thoroughly than I would have been otherwise

I was happy to take part in this trial/research study, in the hope that it will help others and myself.

It seems like a bit like pot luck! If there is a study that might be particularly helpful to my cancer