

Research Participant Survey 2016/7

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Purpose

To describe the results of a Research Participant Survey carried out Nov – Dec 2016 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. Further information available [here](#). A small-scale exercise was carried out in 2015/6 and this included 6 patients from the Lister. Results from the 2015/6 surveys carried out across the East of England (including the Trust) can be found [here](#).

Approach

1. During the period Nov – Dec 2016 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, full details can be found [here](#).
3. In the survey there is a question "Payment (for travel or time) is a factor in my decision to assist with research" which has caused some confusion. At the Trust this relates to reimbursement for parking and travel expenses rather payment to participate in research.
4. 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 100 surveys were completed by the research participants with numerical data provided in Appendix 1 and the comments provided are given in Appendix 2.
- A total of 57 comments were received and included "*I am happy to take part in the Research so that the study can help future treatments. I am completely satisfied with the care and support provided to me by the staff*".
- Looking at all of the 57 the comments, 52 (91%) were positive. Of the 5 (9%) that were negative a total of 4 of these related to difficulties in parking.
- All research participants (100%) said they strongly agreed or agreed with "*I fully understood what I was consenting to*".
- When asked "*Overall, how would you rate your experience of taking part in research on a scale of 1 to 10 with 1 being very poor and 10 being excellent*" 69 responded with a score of 10 as Excellent, the remainder all responded with a score of 7 or more.

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 2017/8.
5. This report was discussed by the R&D Board on 8th March 2017

Appendix 1: Results of the Survey based on the 100 responses

Section 1 Taking Part						
	Beginning	Middle	End	Don't know	No answer	
1. At what stage of taking part in the research are you?	13	48	33	5	1	
	Strongly Agree	Agree	Not Sure	Disagree	Strongly disagree	No answer
2. The study was explained to me in a way that I understood (e.g. using words I understand)	74	26	0	0	0	0
3. I fully understood what I was consenting to	75	25	0	0	0	0
4. It was explained to me that my care would not change if I decided not to take part in the study	78	20	2	0	0	0
5. My questions were answered in a way that I could understand	78	21	1	0	0	0
6. I was kept well informed throughout the study	80	18	2	0	0	0
7. I felt the research staff put my needs first during the study	82	18	0	0	0	0
8 I felt I was listened to by the research staff	86	12	1	0	0	1
Section 2 Taking Part						
	Strongly Agree	Agree	Not Sure	Disagree	Strongly disagree	No answer
9. I was happy with the time and date of my appointment	73	27	0	0	0	0
	Yes	No	No answer			
10. Were you able to choose an alternative date for your appointment	80	5	15			
	Strongly Agree	Agree	Not Sure	Disagree	Strongly disagree	No answer
11. Getting to my appointment was easy (e.g. parking, travelling)	34	55	4	6		1
12. Payment (for travel or time) is a factor in my decision to assist with research	17	9	5	39	25	5
Section 3 Finding out information						
	Strongly Agree	Agree	Not Sure	Disagree	Strongly disagree	No answer
13. I know how to find out the results of the study I took part in	35	31	28	3	1	2
	Letter	Poster	Website	Other	No answer	
14. How would you like to hear about new studies, e.g. letter poster, website etc:	39		12	14	35	
Section 4 Your experience						
	Yes	No	Maybe	No answer		
15. Would you consider taking part in another research study if you had the opportunity?	82	2	15	1		
16. Would you recommend taking part in research to other people?	90	1	8	1		
	1 -very poor -6	7	8	9	Excellent-10	No answer
17. Overall, how would you rate your experience of taking part in research?	0	3	7	20	69	1
	By myself	I had help from friends or family	I had help from staff	other	no answer	
18. Have you completed this questionnaire yourself or did you have help?	93	4	2	0	1	

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

Positive Comments

- *The specialist nurse was particularly helpful and I have nothing but praise for her.*
- *Selfishly I think it has been very beneficial for my condition – and I had frequent opportunities to discuss progress.*
- *I am happy to help in any way and am grateful for the care and treatment.*
- *Could not fault, fantastic staff and consultant, doctors, nurses.*
- *Wonderful caring staff!*
- *I am happy to take part in the Research so that the study can help future treatments. I am completely satisfied with the care and support provided to me by the staff.*
- *The staff were always available by e-mail and telephone.*
- *I was very happy with the help and support I received from all staff.*
- *The fact I am not being paid did not influence my decision.*
- *Transport was supplied.*
- *The reason I attend is for my condition. Any monies received for travel is an added bonus but would change my mind.*
- *There seem to be many research studies available and when the time comes to change I would discuss and suggest them. A number of friends have my problem and I would not hesitate to advise them.*
- *My treatment has been excellent.*
- *I got more attention and better care via taking part in the study.*
- *The research nurses and doctors involved in the study have been amazing and have kept me well informed throughout.*
- *Appointment times were convenient and worked out with my involvement.*
- *I've had a very good experience and it's improved my health.*
- *Good relationship – interpersonal skills of research nurse excellent, and include a home visit to provide a replacement monitor on a Saturday (my need as research participant!).*
- *Payment is appreciated but not a deciding factor in taking part.*
- *Excellent care by all staff. Thank you to all so much.*
- *Would have done it without payment.*
- *Always got an answer when phoning or in the odd occasion I left a message, I always got a call back.*
- *I didn't have any negative experiences because it was all done at the same time as my regular chemo.*
- *The nurses were absolutely lovely, they listened and explained everything to me and also gave very good advice on caring for myself.*
- *So far treatment I have been given has been excellent and hope it continues.*
- *Found staff very good.*
- *Had no problems during the study.*
- *Research staff would answer questions, often finding out the answers and getting straight back to me. This was very important to me to know what is going on.*

- *Taking part has been positive. I have been able to ask questions and be closely monitored by research nurses.*
- *My research nurse has always been supportive, kind and caring and has always listened to my thoughts, doubts and concerns and has always put my mind at ease. She makes my 2 week treatments bearable.*
- *My choice to take part in the trial was only to try to give myself a way forward to hopefully eradicate my cancer. The payment for travel is a bonus.*
- *Fabulous team.*
- *All staff have been great.*
- *Changes in my health are always discussed in detail. I am always listened to.*
- *All of the team provide very good care and are most helpful for all aspects of my treatment.*
- *Excellent staff, felt complete trust in them. Car park fees greatly accepted.*
- *Nurses have been the virtue of a good carer, they listen to what you have to say!*
- *Nursing staff explained and listened to what I had to say.*
- *Opportunity to improve health was driving factor but payment was a bonus.*
- *The staff have been wonderful – helpful and pleasant to deal with – thank you!*
- *Times were flexible so easy to fit in with work.*
- *All staff have been very supportive and proactive in making sure blood/ketone readings when high are dealt with and to check on general health.*
- *Staff always return calls or emails if I had a query.*
- *It's nice to be reimbursed for the travel costs and parking but I would probably still have done the trial anyway.*
- *The research staff were genuinely interested in the well-being of the patients.*
- *I would love to take part in another research study, it is for the community.*
- *The nurses have been fantastic, the care they show to me knows no bounds. They are angels!*
- *Could not have better treatment.*
- *Always treated well and reassured.*
- *Whenever my wife asked a question it was always answered carefully.*
- *I am grateful to be on the trial. Payment is of no importance to me.*
- *I am so blessed to have been included on the trial. It has ensured that I was able to see my grandchildren.*

Negative Comments

- *Car parking at Mount Vernon is notoriously difficult but one works out a way round.*
- *Parking is often a problem at Mount Vernon.*
- *There seems to be some lack of communication between research staff and the chemo suite.*
- *Parking at hospital is a problem. Have to come on bus.*
- *Parking can be a bit of a nightmare, but there are usually empty spaces if you hunt for them.*