

Developing Our Research and Innovation Strategy

Patient Questionnaire

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Contents

Introduction	p3
Aims and Objectives	p3
Sample	p3
Methodology	p3
Results	p4
Discussion	p6
Conclusion	p8
Recommendations	p8
Appendices	p9

Introduction

We are currently developing our Research and Innovation Strategy which will outline our priorities and intentions to maximise our potential to improve and deliver best value, seamless care working with our partners over the next five years. Improving patient outcomes is why we do research, therefore, we asked patients to complete a questionnaire to understand how we can improve patient experience and offer equal opportunities to take part in research and innovation practices. Please see "Developing our Research and Innovation Strategy Patient Questionnaire" (Appendix 1).

Aims and Objectives

A patient questionnaire was developed to enable patients to provide feedback in regards to their knowledge and experience of research and innovation at Wirral University Teaching Hospital NHS Foundation Trust (WUTH). Patients were asked to consider their knowledge of the importance of research and innovation at WUTH, their experience of opportunities to participate in research, and the benefits of participating in research as part of their care. Patients were also asked if they had previously taken part in research at WUTH and if they had been, if they would be willing to participate in a focus group. The aim of the questionnaire was to gain a patient perspective in identifying ways in which we can enhance research and innovation within the trust in order to improve the patient experience.

Sample

There were a total of 65 respondents and the results were anonymous. The questionnaire was not limited to a particular sample group, and was aimed at the wider patient audience to gain as many responses as possible.

Methodology

Below are the steps taken to gain patient feedback:

1. Our Research Manager and Strategy and Business Planning Manager adapted a patient questionnaire previously developed by Royal Free NHS Foundation Trust.
2. The patient questionnaire was reviewed and approved by the Research Department.
3. The Patient Experience Team then developed an electronic questionnaire using a system called Envoy.
4. The link to the electronic questionnaire was then shared and made available for patients to access via social media platforms, and was shared by Healthwatch Wirral social media pages.

5. Posters advertising the questionnaire and a QR Code were put up around both Arrowe Park and Clatterbridge Hospital sites in waiting areas and ward areas.
6. The Research Department also shared paper copies of the questionnaire with patients who were involved in research at the time.
6. The questionnaire remained live for four weeks before closing.
7. Once the questionnaire closed the data was collected and collated. Please see "Patient Questionnaire Results" (Appendix 2)
8. Patient feedback was used to inform our Research and Innovation Strategy.

Results

A total of 65 patients responded to the questionnaire. One question received more than 65 responses, as patients were able to select multiple responses. Patients were also able to skip questions, and other questions were follow-up questions for certain responses given, so received less responses. Details of the numbers of responses to each question can be seen in the raw data in Appendix 2.

Section A

When asked if they agreed that clinical research is currently a key priority for WUTH, 31% of respondents strongly agreed and a further 28% agreed. 29% of patients reported they were impartial, whilst 8% reported that they disagreed, and 4% strongly disagreed with this statement.

Patients were then asked if they thought that clinical research should be a key priority for WUTH, and the majority of patients were in favour of this, with 58% reporting they strongly agreed, and 38% agreeing. Only 2% of patients disagreed that clinical research should be a priority for WUTH, and 2% of respondents were impartial.

74% of patients strongly agreed that clinical research plays an important role in improving patient outcomes and quality of care, and a further 23% agreed. Only 3% of patients reported they were impartial to this, and no patients were in disagreement.

Patients were asked if they agreed that they have the opportunity to participate in clinical research at WUTH, the responses were mixed; only 17% of patients strongly agreed and 16% agreed. 31% of patients reported they were impartial to this question, 27% disagreed and a further 9% strongly disagreed that they have the opportunity to participate in research at WUTH.

Similarly, when considering if they would know who to approach if they wanted to participate in, or find out more about participating in clinical research at WUTH, 40% of patients disagreed and a further 26% strongly disagreed. 12% of respondents were impartial to this statement, 10% agreed, and 12% strongly agreed.

46% of patients agreed, and a further 23% strongly agreed that participating in clinical research would improve their experience of being a patient at WUTH. 28% of

respondents were impartial to this, and only 3% of patients disagreed that participating in research would improve their experience of being a patient at WUTH.

When considering whether patients should be involved in planning research, the majority of respondents were in favour. 31% of respondents strongly agreed and 43% agreed with this. 15% of patients were impartial, 8% disagreed, and 3% strongly disagree that patients should be involved in planning research at WUTH.

When asked about equal access to research, patient responses were again mostly in agreement that all patients at our hospitals should have the same access to clinical research opportunities, 52% strongly agreed, and a further 38% agreed. Only 2% of respondents disagreed, 2% strongly disagreed, and 6% reported they were impartial to this.

Patients were asked if they agreed if it would be good for patients to have the opportunity to consent to be contacted in advance about future clinical research studies that they may be able to participate in. 52% of respondents strongly agreed, and 43% agreed that this would be good. 3% of patients were impartial, and only 2% disagreed.

Finally, patients were asked if they were aware that WUTH has a research department that recruits to national and local clinical research studies, 75% of the responses were for no, and 25% responses indicated yes. Patients who selected yes were then asked if there is a department or an individual that they could name that are linked to research in the trust. Of the 17 patients who selected yes, 5 responded and gave the following answers:

- Respiratory (Dr Wight)
- Fiona Brailsford
- Research Department. I am only aware of this as a former WUTH employee
- No all the ones I knew left to go to other hospitals
- Parkinson's

Section B

Patients were asked if they had ever taken part in research at WUTH. 61 patients responded, 10% of these selected, yes, and 90% selected no.

Of the 6 patients who reported they had taken part in research, 2 reported that they strongly agreed that participating improved their experience of being a patient at WUTH, 3 agreed, and 1 was impartial. None of the patients who had participated in clinical research at WUTH were interested in taking part in a focus group to share their experience.

Patients were asked to leave any other comments at the end of the questionnaire, 10 patients left responses as follows:

- I had no idea there was a research department and have never been asked my opinion about anything while using hospital services.
- I would be interested in helping research. Not much is realised to general public as far as I'm aware.

- Fortunately I have never been ill with a serious condition but would always want to help with research
- I would like to be considered for any appropriate research
- Clinical research is at the cutting edge of new treatment and medicine. If APH developed a university status this would help with future development.
- I am not aware of Clinical Research at the hospital . Maybe if I was a patient there I would have access to the information.
- Clinical research is not a valid indicator for patient safety. It must be separately proposed to patients rather than being placed in the pre-op consent forms. That is not consent, more like coercion into consent. Ethics and codes of practice prevent any such practice, but your pre-op consent forms do not follow this standard. As long as consent is taken by following the highest ethics standards, you can then think about promoting your clinical research areas. Forced consent is not appropriate and it does not promote equality and inclusion in research participation.
- I've been a patient multiple times at WUTH and never had any contact regarding research. I later found out about studies via social media from other NHS providers that I would have been eligible for. I was disappointed that I didn't have the opportunity to participate at the time.
- If research opportunities were promoted externally, it would give members of the public an opportunity to participate. I don't think this is done now and if so, could be done better
- I'm newly diagnosed with Crohn's. I would love to take part in any studies that might improve care for people with my condition especially around mental health and access to better care for people with IBD. I'd love to know if there is anything available for me to get involved with, as it hasn't been mentioned at appointments and when I've looked at the Crohn's and Colitis Website most clinical trials are in the south around London. Nothing seems to be based in the North West hospitals in relation to IBD.

Limitations

A limitation acknowledged is that due to a small sample size, the results may not be widely generalisable, or representative of the wider population, therefore, continued patient engagement is recommended. Secondly, the feedback gained from this questionnaire is mostly quantitative, in order to gain a deeper understanding in to patient experiences, more qualitative feedback would be beneficial.

Discussion

The results are split into two sections that explored the role of research, patients' views of participating in research in general, and patients participation in research at WUTH.

Section A

The role of research

Patients were generally in agreement that Clinical research is currently a key priority for WUTH, however responses were somewhat mixed and 29% reported they were impartial to this concept. This may be due to patients being unsure or not knowing, and the options for responses did not offer this to be portrayed. On the other hand, when asked if clinical research *should* be a key priority for WUTH, almost all patients selected strongly agree or agree, no patients disagreed and only 3% (a total of two patients) were impartial.

Participating in research

Patients were asked if they agreed that they had the opportunity to participate in research at WUTH, responses were mixed, a total of 33% were in agreement, and 36% were in disagreement. 31% of patients reported they were impartial. These results are quite ambiguous; therefore it is difficult to draw a conclusion from this.

When asked if they knew who to approach if they wanted to participate in, or find out more about clinical research at WUTH, more patients disagreed than agreed. A total of 66% of patients reported that they either disagreed or strongly disagreed with knowing who to approach, whilst a total of 22% either agreed or strongly agreed. Just 5 free text comments were received from the sample to name an individual or department linked to research in the Trust, 1 was a staff member from the research department, another highlighted the research department itself but only due to being a previous WUTH employee. 2 comments highlighted clinical areas: respiratory and Parkinson's, and the last highlighted that the individuals they knew had left the trust. One of the free text comments highlighted that the patient had been treated at WUTH and not been offered the chance to participate in research, but had later seen opportunities that they were eligible for advertised by other NHS providers through social media platforms. Similarly, another comment highlighted that a patient had been searching for opportunities online but couldn't find any at WUTH, only in other areas.

The majority of patients were in agreement that participating in clinical research would improve their experience of being a patient at WUTH, with 69% reporting that they either agreed or strongly agreed. Just 3% of patients disagreed, and the remaining 28% were impartial. 5 out of the 10 free text responses noted that the patient would be interested to take part in research. In addition, patients' responses indicated they were in favour of being involved in planning research at WUTH, with a total of 74% either agreeing or strongly agreeing that patients should be involved, compared to 11% of respondents either disagreeing or strongly disagreeing.

90% of patients reported that they either agreed or strongly agreed that all patients at our hospital sites should have the same access to clinical research. 95% of patients agreed or strongly agreed that it would be good for patients to have the opportunity to consent to be contacted in advance about future clinical research studies that they may be able to participate in. 1 patient disagreed with this, and one free text comment appeared to relate to this question, and suggested that asking about participating in research in an example of a pre-op consent forms would be seen as coercion into consent and highlighted the importance of considering ethical standards in relation to consent.

Unfortunately, only 25% of respondents were aware of the research department at WUTH, with 75% reporting they were not aware of our department that recruits to national and local clinical research studies. This was supported in the free text comments, where 4 out of the 10 comments expressed that patients “had no idea” or were “not aware” of clinical research or the research department at WUTH.

Section B

Participating in research at WUTH

61 patients responded to the question asking if they have ever taken part in research at WUTH, only 6 of these patients had. Those 6 went on to consider if participating in clinical research has improved their experience as a patient, none of them were in disagreement, 2 strongly agreed, 3 agreed and 1 was impartial. Unfortunately, none of those patients were willing to take part in a focus group to discuss their experiences.

Interestingly, 6 out of the 10 free text responses highlighted the need for information to be shared regarding research opportunities for patients, sharing lack of general awareness, and the possibilities for increasing awareness as a trust. Patients mentioned various channels of communication such as information on hospital sites, social media platforms, external promotions, and websites.

Conclusion

Despite a relatively small sample size, there are some strong responses from the results of this questionnaire, such as expressed interest to participate in research, and a strong perception that research can improve care for patients. It is important to acknowledge the lack of awareness of research and innovation activities currently at WUTH, and the need to improve the visibility of this in the future.

Recommendations

- Due to the small sample size, further patient engagement should be carried out.
- The results of this questionnaire are mostly quantitative. Some interesting concepts came from the qualitative feedback in the free text response, and a focus group with patients who have taken part into research would offer more detailed insight into patient experience in research.
- Even from a small sample group, it was interesting to note that there is a lot of interest for patients to be involved in research.
- It can be taken from this questionnaire that focus should be given to increasing the visibility of research and innovation activity at WUTH, with particular consideration around methods of communication including social media and digital platforms.

Appendix 1

Developing our Research and Innovation Strategy Patient Questionnaire



Appendix 2

Research and Innovation Strategy Patient Questionnaire Results

