Specialist Nurses’ Perceptions of the Barriers and Facilitators to Inviting Patients to Participate in Clinical Research Studies

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Executive Summary

This summary gives an overview of the research study I carried out for my MRes Clinical Research dissertation between September 2014 and September 2015. I have produced this summary in order to share findings with participants, collaborators, colleagues, and anybody else with an interest in patient recruitment into research.

As a research nurse I was interested in how we can increase the number and diversity of patients participating in research studies. I therefore decided to undertake this study with the aim of identifying possible methods of facilitating specialist nurses, and other healthcare professionals, to invite patients to research.

Please feel free to share this with any colleagues who may be interested. If you have any comments, questions or would like to discuss any aspect of this study I would love to hear from you so do get in touch!

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| **Background** | Increasing NHS patient participation in clinical research studies is a current priority. Healthcare professionals play an important role in inviting patients to participate in research studies. |
| **Research Aim** | To explore the barriers and facilitators perceived by specialist nurses to inviting adult NHS patients to participate in research studies during clinical care delivery |
| **Study Design** | Cross-sectional qualitative descriptive using purposive/convenience sampling, semi-structured individual interviews and Framework thematic analysis. |
| **Participants** | 12 specialist nurses with current or recent experience of inviting adult NHS patients to participate in a wide variety of research studies. Participants came from 7 different clinical specialties and 7 different NHS Trusts. |
| **Results** | Specialist nurses described a wide range of barriers and facilitators, which were often complex and interdependent. Five main themes were identified:  
  - Assessing patient suitability and gatekeeping  
  - Teamwork  
  - Valuing research  
  - A satisfactory invitation process  
  - Understanding the study |
| **Conclusions** | Findings may be a useful basis for reflection to specialist nurses, clinical staff, research teams and policymakers. Recommendations for practice are drawn. |
Background

Recruiting sufficient patients to take part in research studies is challenging, and a considerable number of studies fail as they do not recruit enough participants. Healthcare professionals often play a vital role in recruitment by inviting patients to take part in research when delivering clinical care. It is widely recognised however that healthcare professionals sometimes do not invite all eligible patients, and this can then limit recruitment\(^1\)\(^2\).

Several previous studies have identified barriers and facilitators to healthcare professionals inviting patients to participate in research. This study aimed to address two gaps in this literature:

- Perceptions of specialist nurses.
- Perceptions of inviting patients to research as a general concept, rather than to a specific study. Most previous research has investigated barriers and facilitators to inviting patients to a specific study, usually a randomised controlled trial.

Research Aim

- To explore the barriers and facilitators perceived by specialist nurses to inviting adult NHS patients to participate in research studies during clinical care delivery.

Research Objectives

- To identify, and increase understanding of, barriers and facilitators that could be addressed, sustained or implemented in order to facilitate specialist nurses to invite adult NHS patients to participate in research studies.

Why the study is important

- It is a UK government and NHS priority for more patients to be involved in research.
- The NHS Constitution pledges that all patients will be informed about suitable research studies.
- The reputation of NHS Trusts is enhanced by research activity, and Trusts receive funding for recruiting patients into studies.
- Patients, clinicians, researchers and the general population benefit from successfully completed research studies.

Study Design

I interviewed 12 specialist nurses (between March and July 2015) about their experiences of inviting patients to participate in research studies, and their views regarding barriers and facilitators. I based the interview questions on findings of previous similar studies, which suggest that barriers and facilitators to inviting patients to research may broadly exist at five different levels:

| Patient factors | Study Factors | Research Team Factors | Individual Healthcare Professional Factors | Contextual Factors in Clinical Setting |


I analysed transcripts of the interviews using the Framework method of thematic analysis. Briefly, this involved firstly categorising and indexing the data into main categories and subcategories, and then identifying cross-cutting themes and subthemes.

**Design Summary:** Cross-sectional qualitative descriptive study, using purposive and convenience sampling, semi-structured individual interviews and Framework thematic analysis.

**Who participated in the study?**

The main inclusion criteria were being a specialist nurse in an acute or community NHS Trust, with current or recent experience of inviting adult patients to participate in research studies. I only included nurses who invited patients within the remit of their clinical roles, rather than nurses who had dedicated research roles.

12 specialist nurses participated, from 7 different acute or community NHS Trusts. Participants worked in 7 different clinical specialties: stroke, HIV, cardiac prevention/rehabilitation, Parkinson’s disease, pulmonary hypertension, vascular surgery and cancer.

**Results**

From the interview data I identified five main themes of barriers and facilitators to inviting patients to participate in research studies. The barriers and facilitators within each theme were often interdependent across and within the themes, and specialist nurses had variety of perceptions.

### ASSESSING PATIENT SUITABILITY AND GATEKEEPING

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td>• Belief patient should be protected from anticipated negative consequences e.g. emotions, burden.</td>
<td>• Anticipating positive impacts on the patient</td>
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<tr>
<td>• Desire to avoid negative impacts on research study by inviting patients perceived as unsuitable</td>
<td>• Belief all eligible patients should be offered choice of research participation</td>
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<td>• Lack of reassurance from research team about impacts of studies on patients</td>
<td>• Clinical team culture of inviting all eligible patients</td>
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<td>• Limited opportunities to time the invitation sensitively</td>
<td>• Ability to time the invitation sensitively</td>
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<tr>
<td>• Not wishing to raise false hopes for patient</td>
<td>• Ability to use trust and rapport from clinical relationship to minimise patients’ potential negative emotions</td>
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...it’s the quality of the data afterwards is the important thing really, and if they can’t participate in giving the right kind of data then I think it’s probably not a good person to recruit

...I think sometimes we can be a bit paternalistic thinking there’s too much going on, when actually patients want to take part and improve things.
### TEAMWORK

<table>
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<th>Barriers</th>
<th>Facilitators</th>
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<tr>
<td>- Poor sense of teamwork within clinical team</td>
<td>- Good sense of teamwork within clinical team</td>
</tr>
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<td>- Patients receiving conflicting information from clinical team</td>
<td>- Unified approach to inviting patients within clinical team</td>
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<td>- Poor sense of teamwork with research team</td>
<td>- Good sense of teamwork with research team</td>
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<td>- Sense research team not playing their part</td>
<td>- Close, positive, longstanding relationships with research teams</td>
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<td>- Poor communication and lack of feedback from research team</td>
<td>- Researcher embedded in clinical team</td>
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<td>- Research team external and not easily accessible / approachable.</td>
<td>- Sense of mutual collaboration and respect between research team and specialist nurse / clinical team</td>
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<td>- Research team providing appropriate resources to support specialist nurses inviting patients</td>
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I remember identifying maybe 15 patients...obviously I got a thank you, but didn’t hear anything back about whether that had been helpful or not...then it’s really hard to know, am I going to keep using my time in that way?

If we didn’t have such close relationships with them I think it would be, we probably wouldn’t be quite so motivated into recruiting...

### VALUING RESEARCH

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<th>Facilitators</th>
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<tr>
<td>- Lack of wider research culture</td>
<td>- Personal valuing of research</td>
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<td>- Research teams not clarifying relevance of inviting patients to clinical practice development, e.g. not feeding back study results</td>
<td>- Experience and knowledge that highlight links between inviting patients to studies and improvements in care</td>
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<td>- Overriding clinical priorities within the specialist nurse role</td>
<td>- Inviting patients to research seen as relevant and valuable to specialist nurse role</td>
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<td>- Flexibility and autonomy within role</td>
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<td></td>
<td>- Positive wider research culture (in NHS / Trust / specialty)</td>
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<td>- Positive local research culture</td>
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Often you never hear the results of that study...I feel like you never hear the bigger picture, you always just hear this is what we need today

...going to conferences and things and finding out about different studies that have happened. And you think, oh well that’s actually made a real improvement because you can see this has developed...

...I think you almost have to come through the cycle to see the impact of one of those studies and what it has now done, and how surgery has changed because of that study to fully see the benefit...
What do these findings mean?

The barriers and facilitators were broadly in accordance with previous research findings relating to other healthcare professionals, however this study gave several new insights into facilitators. The findings may provide a basis for reflection for research teams, specialist nurses, clinical teams and policymakers with an interest in increasing patient research participation.

It is however important to consider potential limitations of this study:

- All of the participants in this study held positive views about research, which means that the views of specialist nurses with negative or ambivalent views were not represented.
- It is possible that I, as the researcher, may have influenced the data and findings through my preconceptions, although I took measures such as reflexivity and double coding of transcripts to address this.
Key Recommendations

For specialist nurses / clinical staff

- Reflect on personal and professional attitudes to judging patient suitability for studies, and seek support from experienced colleagues and research teams.
- Seek resolution of concerns about studies with research teams.
- Reflect on teamwork and strategies regarding inviting patients to participate in studies within the local clinical team.
- Proactively engage with research teams and seek to build positive relationships.
- Articulate own requirements for invitation processes and study education to researchers, and provide constructive feedback.
- Seek opportunities to extend own research knowledge and experience, particularly relating to links between research and practice development.
- Seek patient feedback on experiences of research participation and being invited to participate in research.

For researchers / research teams

- Anticipate and discuss potential gatekeeping issues with specialist nurses and clinical teams.
- Seek and utilise all opportunities to build positive local relationships with specialist nurses and clinical teams.
- Engage with specialist nurses from an early stage and throughout the collaboration to promote understanding of studies, how inviting patients links to practice development, and to create a mutually satisfactory invitation process. Seek feedback to ensure support and education are optimal.
- Tailor support and education to individual specialist nurses’ and clinical teams’ preferences / requirements where possible.
- Ensure all communication and behaviour conveys a sense of teamwork with specialist nurses and clinical teams.
- Help promote wider research culture and enthusiasm for research beyond own study.
- Nurture relationships with specialist nurses and seek to learn from their expertise in sensitively inviting patients to participate in research.
For policymakers / managers

- Provide training and support for specialist nurses and other clinicians to reflect on gatekeeping, and increase confidence to invite patients to studies in challenging circumstances.
- Continue to publicise patients’ experiences of research.
- Continue to promote broad measures to establish clinical-academic partnerships, and consider increasing promotion and support to establish these partnerships at the local clinical team level.
- Consider measures to broadly promote research awareness and the clinical relevance of research participation to clinical staff.
- Consider how to provide clinical working conditions conducive to inviting patients to research.

Thank you very much for taking the time to read this research summary and I hope you find it useful. Please do not hesitate to contact me if you have any questions or comments.

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Acknowledgements

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