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# Reflections on involvement in health research: a qualitative interview study with NMAHPP research participants and patient advisors

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NMAHPP - Nursing, Midwifery, Allied health professions, Healthcare sciences, Pharmacy, and Psychology

### 1. Background and purpose

Existing literature on healthcare research participation focuses on the reasons why people do, or do not, take part in a study. The concept of participant-perceived research impact has not previously been explored.

The aims of this study were to:

- (i) Explore individuals' experiences of being involved in NMAHPP healthcare research, and
- (ii) Identify the types of impact that are important for participants and patient advisors.

Study approval: NHS REC 21/WA/0229, IRAS 298078

#### 2. Methods



Twenty-one individuals were recruited from five UK sites and via social media. Each took part in a 1:1 semi-structured interview, conducted via phone or video call.



Interviews were audio recorded and the transcripts analysed using Thematic Analysis. Four key themes and subthemes were created to illustrate both the collective and unique experiences of interviewees. Themes were developed with interviewee feedback.

#### 3. Results

## OPTIMISING RESEARCH EXPERIENCES

"I didn't realise there
wasn't a gap in the time
to have a sandwich. I
remember saying: it's
lunchtime now and I'm
really quite hungry"
#2, male, 50-69yrs, participant

"Let them know what they are doing is so important, they are so important"

#19, female, 70-89yrs, advisor

Included personal reflections and broader recommendations to improve participant experiences.

# CONNECTING RESEARCH WITH HEALTHCARE

"Research is valuable
and should be timed into
[clinicians'] schedules"
#9, female, ≤49yrs, participant

"A really interesting study... but things didn't go back to the doctors, there wasn't the twoway flow"

#15, female, ≤49yrs, participant & advisor

Described research-active NMAHPPs as key for the continued development of healthcare, but illustrated that communication between research and clinical teams could be improved.

# PERSONAL IMPACTS OF RESEARCH INVOLVEMENT

"It feels good. I really
like the idea of being
able to help people"
#10, male, ≤49yrs, participant & advisor

"It was nice to meet other people with the same problem"

#3, female, 50-69yrs, participant

"Part of my reason for doing it... I'd not had any proper tests done for a while"

#7 male, ≤49yrs, participant

Recalled common positive experiences of research involvement, with different drivers for participation.

# CAPTURING RESEARCH IMPACTS

"Commissioners love objective data! Less visits, less time...turn subjective opinions into objective data to keep the commissioning people happy"

#1, male, 50-69yrs, participant

"The proof of the pudding is when the patient gets to eat it, and how well it tastes for them"

#11, female, 50-69yrs, participant & advisor

Highlighted the needs of different stakeholders, but emphasised that financial impacts should not be the sole factor.

#### 4. Conclusions

Individuals who were involved in NMAHPP health research recalled positive experience and reported good relationships with their research teams. They felt that their contributions were valued.

Suggested strategies to optimise the research experience focused on:

- Simplifying documentation
- Clear signposting of the research activities involved
- Feedback on the research findings
- Routinely sharing research findings with participants' clinicians.

Personal impacts included deeper understand of their own health condition, or health more broadly, and increased confidence interacting with healthcare and other professionals.

## 5. Next steps

These findings have been combined with our previous work exploring research impact from the perspectives of healthcare managers and research-active NMAHPPs. The collective data were used to develop a framework and tool to capture the impact of NMAHPP research. This was piloted in late 2022 and the results will be out soon!

#### 6. Funding

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## 7. Associated publications

Systematic review of NMAHPP research impacts. *BMC Health Ser Res* 2021; 21:400 <a href="https://doi.org/10.1186/s12913-021-06354-y">https://doi.org/10.1186/s12913-021-06354-y</a> Interviews with healthcare managers and research-active NMAHPPs. *BMJ Open* 2021; 11:e050679 <a href="https://bmjopen.bmj.com/content/11/10/e050679">https://bmjopen.bmj.com/content/11/10/e050679</a>





