

it is About US!

Patient Engagement in Health Research



Research Question

How do arthritis patients' view and experience the process of engaging in research?



Methods

Design guided by established participatory action research approach

Memorandum of Understanding between academic researchers and Arthritis Patient Advisory Board (patient partners)

Eligible participants were APAB members who had engaged in research

In-depth interviews focused on 3 areas:

- 1) experiences of being a patient engaging in research;
- 2) interactions with researchers;
- 3) perspectives on the advisory board's development.

Data analysis uses an iterative, constant comparison approach to extract key findings from interview transcripts, assisted by NVivo software to track and summarize coded data

Conclusions

Findings demonstrate:

- barriers and facilitators to patient engagement in research, from patients' perspectives
- a gap to be filled in shaping how research is created, shared, and used.

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Background

"nothing about us without us" – empowering patients and public to engage with researchers to ensure relevant research and better health outcomes

Patients engaged from defining research question to dissemination of findings.

Patients & public are critical to knowledge translation – both to share and use research findings that matter to them.

Arthritis Patient Advisory Board (APAB) is a group that aims to make "nothing about us without us" happen in the research ecosystem



Preliminary Results

22 out of 33 eligible participants were recruited (18 current APAB members, 4 past APAB members), with 1 mth to 10 yrs of experience of patient collaboration in research. Aged 26-68 (median 60 years). 12 reported inflammatory arthritis, 5 reported osteoarthritis, and 4 reported both (1 did not report diagnosis).

Three key themes emerging from data:

- 1) **being heard** by the senior researchers, and being able to voice "things that matter to patients"
- 2) **"adding another spinning plate to an already busy life"**: the volunteer workload of engaging in research could exacerbate stress or disease symptoms, yet most said benefits like "helping others" outweighed downsides
- 3) **building social relations**, including solidarity with peers on APAB, and for some, being on a first-name basis with a researcher "talking about his research as casually as if he was at a Sunday picnic" was a "culture shock"



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