

Background

- Patient engagement in research refers to different types of activity through which patients participate in decision-making at any stage of a research process.¹
- It has an ethical basis in the notion that patients should have a say, if they choose, in what and how research is undertaken.²
- Building reciprocal relationships between patients and researchers is an essential component of ethical practice in patient engagement in research.³
- Little empirical evidence exists to better understand how to build and maintain good patient-researcher relationships in the everyday practice of patient engagement in research.

Methods

- Designed and conducted jointly by researchers and patient partners
- An in-depth, semi-structured interview in-person or by phone; transcribed verbatim
- Eligible participants:
 - past or present members of Arthritis Research Canada's Arthritis Patient Advisory Board
 - lived in British Columbia
 - were English-speaking
- Thematic analysis using constant comparison methods was carried out.⁴ Member checking and peer checking embedded in the process added rigour.
- A relational ethics lens was applied to emergent themes.

References

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Purpose

- To understand what is valued and at risk in relationships between patients and researchers partnering in research, from the perspectives of people with arthritis

Findings

- 22 out of 33 eligible participants were recruited, with 1 month to 10 years of experience in engagement in research. Aged 26-68 (median 60 years old). 21 were female. 12 reported inflammatory arthritis, 5 reported osteoarthritis, and 4 reported both (1 did not report).

Theme 1: Being Heard

Participants valued mutually respectful relationships in which researchers and patients were heard. For many, this involved giving importance to distinct contributions of patients and researchers in the research process. If patients and researchers were not heard, some participants highlighted there were risks of patients viewing efforts to engage as tokenistic, and the quality of research being negatively affected.



"there have been some research projects where our feedback has made a difference in how the research was designed... that's showing respect to the patient perspective..." (Marie)

"there's a mutual respect... patients sometimes need encouragement and reinforcement that their views are not lesser... that's really important because patients are going to be reticent to contribute if they feel it's tokenism." (Jessica)

"I've seen patients shape some projects... what I saw these investigators had at the end was a much less generalizable project... I don't think that you can discount years of research training for patient experience... we need to figure out the best way to give them both critical weight and maximize each one... The patient is just as important as the researcher, and the researcher is just as important as the patient" (Olivia)

Theme 2: Building supportive relations

Many participants valued building informal, open and reciprocal relations with researchers over time. They also valued researchers who recognized patient partners were juggling the volunteer work of engaging in research among other priorities in their daily lives. Doing so was perceived to alleviate power hierarchy and avoid negative impacts of engaging experienced by patients (e.g., feeling guilty).



"[I was] sent a draft of the newsletter [by a researcher]. Would you have some time to review it before I send... So I think that's really nice... you're not just sent something without a warning and then expected to be able to find time in their deadline to do it" (Jessica)

"Everybody was on a first-name basis and right away that power hierarchy is dismissed. ... We knew a little bit about their families. They knew about ours." (Phoebe Lewis)

"you're already dealing with so much yourself, personally in your home life, your own health, your own work life... if you're not able to contribute to the same degree because you're in a flare, there's a level of understanding and appreciation that you don't have to feel guilty" (Mary)

Conclusion

Findings provide valuable insight into what is important in the process of building good patient-researcher relationships, based on the perspectives of patient partners with varying amounts of experience in patient engagement in research. Findings may serve as a guide for patients who have chronic illness and researchers to realize benefits and mitigate risks that may arise in their engagement with each other. This work is a critical step in supporting ethical practices of patient engagement in research that are meaningful to patients.

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