



Achieving Balance and Diversity in Patient Engagement in Research: Perspectives from Patients

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Background

- Patient engagement in research, where appropriate, seeks collaboration and inclusion of patients in all stages of research
- Democratic ethos: nothing about us without us!
- Improves relevance of research findings
- Tokenism is commonly expressed concern
- There is a lack of understanding of patients' experiences as research partners

Objective

To explore patient perspectives of factors that support or hinder engagement in research

1. Occupational aspects of involvement (relating to daily activities)
2. Societal aspects of involvement (relating to external socioeconomic or environmental conditions)

Methods

- Study was co-developed and conducted with patient partners
- Eligible participants were current or past members of Arthritis Patient Advisory Board at Arthritis Research Canada in Vancouver
- Semi-structured, hour-long interviews conducted in 2015 - 2016
- Thematic "constant comparison" analysis

Findings

Study Demographics

Participant Characteristics	N=22
Age	• 26 – 68 (median = 60)
Experience as Patient Partner	• 1 month to 10 years
Sex	• 21 women • 1 men
Education	• 14 with university degree(s)
Occupational Status	• 12 employed fulltime • 9 retired • 2 students • 2 on disability benefits
Diagnosis	• 12 inflammatory arthritis (IA) • 5 osteoarthritis (OA) • 4 OA and IA

Preliminary Theme 1

Finding purpose and support in volunteer work

Volunteering is rewarding and purposeful, but is a considerable demand on time and energy

Varying levels of need must be addressed to make patient engagement compatible with disease

Representative quotes from participants

*"There's an inherent sense of value that your contributions may make the path a little easier for other people that are similarly having a challenging journey. So it makes you feel like **there's some more purpose in what you're experiencing**. You have to be very cognizant about how to still look after yourself and your disease and all the other things while still contributing"* - Jessica

*"You can sort of be **pulled into that sense of responsibility** that you need to complete the tasks by the deadlines and you feel compelled to do so but sometimes your own health does not permit that and there is a culture within [the advisory board] that **nobody is going to make you feel bad at all when you can't do it**, you just can't do it and people want you to look after yourself."* - Mary

Preliminary Theme 2

Addressing issues of representation

Participants saw the patient advisory board as being representative of differing: Disease severity; Level of experience as a research partner

Some perspectives were seen as lacking from the patient advisory board: Men with arthritis; Marginalized communities; Lower socioeconomic classes; People with limited educational opportunities

Representative quotes from participants

"You need to nurture both naïve or new people as well as have the expert patient. You need to work together and be constantly renewing in order to keep the cycle going because eventually that naïve patient is going to shift and be the expert patient and then they can't bring that perspective of the regular public to what we're doing, so it's a constant renewal." - Julie

*"Diverse socioeconomic status was discussed; however, we **were stumped by how to do it**. It's important to get members who can bring different perspectives. Currently, [the advisory board] doesn't represent all socio-economic groups or education levels. That can be a problem especially since **we see ourselves as the voice of the patient**. Which patient? I think it's important to represent everyone"* - Lori

Implications

- Patient partners benefit from a supportive environment where the constraints of their disease are understood
- Novice and veteran patient partners have different perspectives, both of which are valuable in an advisory board
- Arthritis patients most negatively impacted by the social determinants of health may not be represented on patient advisory boards