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

Study Demographics

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>N=22</th>
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<tbody>
<tr>
<td>Age</td>
<td>26 – 68 (median = 60)</td>
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<tr>
<td>Experience as Patient Partner</td>
<td>1 month to 10 years</td>
</tr>
<tr>
<td>Sex</td>
<td>21 women, 1 men</td>
</tr>
<tr>
<td>Education</td>
<td>14 with university degree(s)</td>
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<tr>
<td>Occupational Status</td>
<td>12 employed fulltime, 6 retired, 2 students, 2 on disability benefits</td>
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<tr>
<td>Diagnosis</td>
<td>8 inflammatory arthritis (IA), 5 osteoarthritis (OA), 4 OA and IA</td>
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Findings

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 patients 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

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 reworking 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

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