

## *Patient Engagement Research Ambassadors' 2024 Community Patient Engagement Report: How we co-created it and some highlights*

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The Institute of Musculoskeletal Health and Arthritis's (IMHA's) Patient Engagement Research Ambassadors (affectionately called "PERA") meet virtually every two months and provide insights and perspectives from their own lived experiences and those from their communities to help IMHA achieve its goals and priorities. One member of PERA has also been a member of IMHA's Institute Advisory Board and has reported regularly to the Board about PERA's work. In 2024, PERA members expressed wanting to share their work beyond the Institute Advisory Board to IMHA's greater community.

The result is the PERA Community Patient Engagement Report. This blog explains the process of developing the report along with what updates are shared in the report.

### Co-creating the Infographic

When members of PERA talked about creating a report, they also brainstormed what should be shared in it and its format. The group decided on a number of topics for the report that reflected the projects they worked on together throughout 2024. They decided that an infographic would be an accessible approach to the report along with a plain language description of it.

Based on the that initial conversation, a patient engagement specialist (DR) who supports PERA's work drafted initial text related to the report's topics, including any numbers or statistics that were needed. PERA members contributed to editing and refining the text at meetings until they felt it was complete. One PERA member (AS) who is experienced with creating infographics used Canva to draft an infographic. The infographic was shared with PERA for their comments and edits, and then the final version was created.

In the end, all PERA members contributed to the co-produced report.

### The Community Patient Engagement Report

There are six sections to the report with each highlighting a key project or initiative (along with lots of links) that PERA members have been involved in throughout 2024. The sections include:

1. A bit about PERA and their membership on IMHA boards, committees or working groups
2. The PxP-PERA webinar series
3. The PxP Conference which is by patients, for patients and all about patient engagement in research
4. Peer-reviewed, published papers that PERA members co-authored
5. How-to Guide for Patient Engagement in Research course, including how many people have taken it and the roles those learners have
6. Workshops about patient engagement in research that were hosted.

PERA members hope others will be inspired by the work they do to either participate in these initiatives or to model their own initiatives and work on this!

### PERA members' highlights in 2024

Just like all of the work PERA does, this blog was co-authored by 3 members of PERA. In their own words, here are a few highlights about their work in 2024:

*“Being a member of CIHR/IMHA as a PERA has been one of the greatest honours of my life. With the strong leadership and guidance from Dawn Richards, Karim Khan, Hetty Mulhall, and the support of the IMHA team, our cohort accomplished so much. We also learned from each other; our expertise, our strengths and passions for better results and outcomes in relation to health care and clinical research. We formed friendships and have collaborated on other projects outside IMHA. We supported and cheered on each other successes. The PxP-PERA webinar series was the greatest success, followed by the PxP Conference which is by patients, for patients. These initiatives demonstrated the depth of expertise, passion and commitment for patient engagement of PERA members.” – Deb Baranec*

*“Being a guest speaker on the second webinar of the PxP-PERA webinar series was a highlight for me! As a newer patient partner, I got to speak about my motivations for being a patient partner and learned a lot about how motivations evolve throughout years of partnership. As a result of being a PERA member, I have learned from all the other members and grown in my personal advocacy and as a patient partner.” – Anna Samson*

*“My role as a PERA member has enhanced both my personal and professional life. It is a joy to engage with my peers and the greater community. Promoting patient partnership in research is so important and I’m honoured that IMHA has allowed me to do so.” – Beth Ciavaglia*