



Integrating lived experience and learned experience on the Journal of Patient Centricity's editorial board

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“The journal can play an important role in encouraging those working in patient involvement, engagement and centricity to feel confident in sharing their work with the academic literature.”

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A patient, a researcher & a medical communications consultant walked into a bar...

Patient researchers or patient scientists are individuals with multiple perspectives of expertise, representing both lived experience and learned experience [1–3].

As someone who represents multiple lived and learned experiences, or who wears ‘multiple hats’ [4], I am pleased to be joining the editorial board of the *Journal of Patient Centricity* to contribute from my perspectives of:

- A patient advocate with lived experience of several chronic conditions including a connective tissue disorder.
- A patient engagement researcher at the Centre for Pharmaceutical Medicine Research, King's College London.
- The head of patient engagement at Twist Medical, a medical publications and communications consultancy that partners with the pharmaceutical industry.
- A patient and public involvement contributor to several initiatives, including the Oxford Patient Engagement Network for Arthritis and Musculoskeletal Conditions (OPEN ARMS) at the University of Oxford, and Sage Publishing's plain language summaries of publications (PLS-P) peer review panel.

Across these roles, my work, personal, professional and academic, is focused on developing and implementing high-quality patient involvement and engagement in pharmaceutical medicine, particularly within the scholarly publications space. Recent academic efforts have included a qualitative landscape mapping of expert perspectives and current industry practices in patient involvement in publications (for example as authors, editorial board members and peer reviewers) [4], as well as a practice-informed systematic literature review and qualitative evidence synthesis of proposed best practices for patient authorship. Current directions include expert consensus methodology to refine and implement these best practices. In the medical communications industry, we innovate real-world solutions in the delivery of the very patient involvement and engagement activities for which these best practices are being developed. We also support other researchers and organizations, for example, pharmaceutical companies, to robustly and compliantly publish their own patient involvement and engagement work in the literature [5].

From my perspectives, patient centricity is a non-negotiable principle for humanizing healthcare and medicines development, ensuring both outcomes and processes are fit-for-purpose and serve the very people and communities that they are intended to benefit. Patient centricity also better enables learned experience researchers and professionals to recognize lived experience as a valid and legitimate epistemological form of knowledge [6,7].

Barriers to entry

Often the first challenge is in recognizing the value of patient involvement, engagement and centrality, though it is becoming increasingly more difficult for the laggards on the adoption curve to justify its absence [8]. However, even with the challenge of recognition overcome, further barriers persist in implementation. One of the most notable barriers is the lack of consistency and standardization in implementation [4], compounded by a lack of awareness of what is possible or not and by the conflicting interpretations of guidelines. For example, industry-level guidelines do not prohibit the remuneration of patients involved as authors for their time spent on authorship activities, in fact several guidelines support this [9,10], yet many pharmaceutical companies have policies prohibiting remuneration in this situation [11,12].

Elsewhere in qualitative patient involvement and engagement research activities, such as the generation of patient experience data, gaps persist in the limited utilization of fully theoretically-grounded, established qualitative methodology accompanied by appropriate ethical review board documentation. Taking these necessary preparation steps to qualitative research design and set-up would strengthen the credibility and rigor and ensure that generated data are of a suitable quality for publishing in the literature. Following recent consultations and calls for inclusion from regulatory agencies [13,14], qualitative patient experience data will begin to be increasingly included in regulatory submissions, and ensuring the quality and credibility of such data will be vital. Similarly, ensuring qualitative patient involvement and engagement work is of high quality and generates publishable data will also help to counter the publication bias that limits the visibility of patient involvement and engagement research in the literature [15].

Taken together, the barriers that persist in patient centrality are less so about an absence of an evidence basis and are more so about gaps in awareness and visibility and in the translation and utilization of established methodologies that inevitably lead to gaps in consistent implementation.

Enter the Journal of Patient Centrality

When the *Journal of Patient Centrality* first reached out to announce its launch and share an invitation to join the editorial board, there was no question as to my response. Qualitative patient involvement and engagement research is an inherently interdisciplinary exercise, and as such it often falls on the peripheries of the aims and scopes of other journals, both those that are biomedical/pharmaceutical and those that are methodological/sociological alike. A scholarly home dedicated to uplifting and showcasing such interdisciplinary work has been sorely needed.

As the *Journal of Patient Centrality* grows and cultivates a body of published work, it will be important to establish expectations of good qualitative methodology and research quality for incoming submissions, including encouraging authors to demonstrate comprehensive and transparent reporting by adhering to the standard requirements of using reporting guidelines and providing ethical review board documentation, as appropriate. The journal can play an important role in encouraging those working in patient involvement, engagement and centrality to feel confident in sharing their work with the academic literature. Options for nonempirical article types such as editorials and commentaries to foster thought leadership and dialogue will also be valuable, as will case studies of good patient involvement and engagement efforts and outcomes. But the biggest opportunity will lie in patient-led and patient-authored work, such as perspective articles, to provide humanized narratives that centre lived experiences.

With multiple patients already embedded in the editorial board representing a variety of experiences, perspectives and expertise, there is substantial opportunity for current and future journal directions and decisions to be shaped by our voices. I commend the *Journal of Patient Centrality* for starting off strong and look forward to seeing what comes next.

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