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Advancing social justice in healthcare publishing: a call to action

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INTRODUCTION

In today's rapidly evolving health and social care landscape, healthcare has become increasingly complex, requiring a grounding in both science and the arts. Integrating these perspectives creates space for more inclusive, creative and contextually grounded approaches to knowledge generation. While calls for social justice in healthcare are gaining traction, the concept is often misunderstood as a redistribution of limited resources. In reality, a social justice lens in healthcare research and publishing is better understood as a process of identifying and removing structural barriers that prevent individuals and communities from achieving optimal health outcomes. Far from being a zero-sum endeavour, this approach can enhance system efficiency, improves quality of care and strengthens trust across populations. These shifts are challenging conventional assumptions about how research is conducted, funded and published, including what counts as evidence, whose voices are legitimised and who shapes research agendas. Increasingly, there is recognition that traditional hierarchies of evidence may not fully capture the complexity of human experience particularly in the context of structural inequities. This has led to growing interest in qualitative, participatory and creative methodologies as well as approaches that centre lived experience.

In this commentary, we explore how health research is evolving through these approaches, the role of lived experience in shaping knowledge production and how funding and publication practices are adapting in response. We consider the implications for researchers, practitioners and policymakers and highlight emerging examples, including those within BMJ Leader, that illustrate the transformative potential of this paradigm shift in advancing social justice in healthcare publishing, with implications for improving equity, quality and trust across health systems.

RESEARCH IN THE MODERN CONTEXT: EXPANDING BEYOND TRADITIONAL METHODS

Historically, health research has been grounded in quantitative methods, such as randomised controlled trials (RCTs), which focus on measurable outcomes.¹ While these methods are invaluable for establishing evidence-based practices, they often do fail to capture the full complexity of human experiences especially as they relate to subjective aspects of health and well-being.² Understanding these subjective experiences, especially

how they are impacted by structural inequities and injustices, is increasingly recognised as critical to meeting the Institute for Health Improvement six quality aims.³ These gaps left by quantitative methodologies have led to the growing recognition of the value of qualitative research, with diverse approaches that prioritise narratives, context and lived experiences.⁴ These shifts also align with broader calls to decolonise global health and medical knowledge production. Decolonising approaches challenge historically dominant epistemologies that privilege Western, biomedical and quantitative paradigms, often at the expense of knowledge systems rooted in lived experience, community practice and non-Western traditions. Emerging scholarship highlights how inequities in authorship, funding and publication reinforce epistemic hierarchies and limit whose knowledge is legitimised.⁵⁻⁷ Engaging with these perspectives strengthens the case for pluralistic approaches to evidence and situates creative and participatory methodologies within a broader movement for epistemic and social justice.⁶

Creative methods such as arts-based research (ABR),⁸ as one genre of qualitative research, have emerged as powerful tools for exploring the emotional, social and psychological factors that affect health. ABR includes a variety of forms such as photography, music, visual arts, poetry or performance, to gather data, analyse findings and present results.⁹ By incorporating these creative methods, researchers can engage participants on a deeper level, which allows them to express experiences that might otherwise have remained unspoken or inaccessible.^{6 10}

SHIFTING POWER IN RESEARCH: THE ROLE OF FUNDERS, PATIENTS AND COMMUNITIES

Research funding is an essential pillar in shaping the direction of scientific inquiry.¹¹ However, traditional funding models often prioritise quantitative studies, principally those with clear, measurable outcomes.¹² This funding structure can inadvertently restrain the development of creative, qualitative or participatory research methods that emphasise personal narratives and understanding of subjective experiences.¹³ As a result, there has been a growing call for funding bodies to shift their priorities and better support creative and lived experience research. The reasons behind this call are varied, from the advancement of work to dismantle structural inequity in health, healthcare

and health education, including the expansion of who leads the research and has influence over the research questions.

Highlighting the increasing value on diverse voices and perspectives are patient and public involvement (PPI) initiatives where members of the public, patients and care partners are actively involved in the design, delivery and interpretation of research and in establishing what research questions should be explored in the first place. Several funding bodies have made structural changes to recognise the value of PPI. The National Institute for Health Research in the UK has made PPI a core component of all research proposals, therefore ensuring that studies are more inclusive and matter to the populations they aim to serve.^{11 14} The Canadian Institutes of Health Research's mandate includes actively engaging patients as partners in health research to improve research relevance and outcomes, supported by the Strategy for Patient-Oriented Research.¹⁵ In the US, the National Institutes of Health is also increasingly prioritising patient engagement in its research funding and activities.¹⁶ However, the integration of PPI within research funding structures is not without critique. While many funders mandate PPI, its implementation can be variable and, at times, tokenistic, with limited influence on research design or decision-making.¹⁷ In some cases, PPI is incorporated into traditional study designs, such as RCTs, without fundamentally shifting underlying power dynamics or epistemological assumptions.¹⁸ Recognising these limitations is essential if PPI is to move beyond procedural inclusion towards genuine co-production and shared authority in knowledge generation.

Funders are additionally beginning to recognise the importance of interdisciplinary research that combines scientific methodologies with creative approaches. Publishers will similarly have to adapt in order to support the review and publication of a diverse range of methods such as narrative inquiry, ethnography and ABR because funders are rapidly moving towards a shift where they can ensure that research addresses not only clinical and biological aspects of health but also the social, cultural and emotional dimensions that impact well-being.¹⁹

LIVED EXPERIENCE RESEARCH: ELEVATING THE VOICES OF THOSE AFFECTED BY HEALTH ISSUES

Lived experience research emphasises the importance of incorporating the personal narratives and insights of individuals directly affected by a condition or issue.²⁰ Rather than treating participants as passive subjects of study, this approach involves them as active contributors to the research process.²¹ In this commentary, we use the term lived experience research to refer to approaches that centre the knowledge, perspectives and interpretive authority of individuals directly affected by health and social care systems. This includes but is not limited to: (1) Qualitative methodologies that elicit experiential narratives (such as interviews, ethnography), (2) Participatory and co-produced research approaches where individuals contribute to study design and analysis and (3) User-led or survivor-led research where people with lived experience hold primary epistemic authority.²²

While overlapping with PPI, lived experience research differs in that it does not position individuals solely as contributors to predefined research agendas, but as knowledge holders and, in some cases, leaders of inquiry. It may also intersect with creative and arts-based methodologies, though these represent distinct methodological traditions with different epistemological foundations.

These distinctions are important, as PPI, participatory research and arts-based approaches operate along a spectrum

of engagement, influence and epistemic authority. Lived experience research is particularly valuable in health and social care as it offers a deeper understanding of how individuals navigate complex systems of care, face challenges and perceive their well-being.^{23 24} The inclusion of lived experience in research can illuminate areas that might otherwise be overlooked in traditional studies.²³ For example, patients with chronic illnesses or mental health conditions can provide invaluable insights into the daily challenges faced, the emotional toll of treatment and the ways they cope with their circumstances.²⁵ These insights are critical for informing patient-centred care practices and improving overall health outcomes.²⁶

Additionally, lived experience research often employs participatory methods where the researcher and participant collaborate closely throughout the study. This co-creation of knowledge ensures that the research is meaningful, relevant, and respectful of the individuals involved, including patients, care partners and community members.²⁷ Especially when giving voice to individuals with one or more systemically excluded identities, lived experience research helps to address health disparities and improve equity in healthcare systems.⁴

CREATIVE METHODS IN RESEARCH: BRINGING NEW PERSPECTIVES

Incorporating art as research helps to bridge the gap between the scientific and humanistic aspects of health. By encouraging participants to engage with their experiences in creative ways, researchers can gain insights into the emotional and psychological impact of a health condition, the social dynamics of care and the broader environmental influences on well-being. ABR has broad applicability and can be applied to a wide range of participants, including patients, care partners, community members, as well as learners, healthcare professionals and staff. For example, a study exploring the mental health experiences of refugees might use photography, storytelling or dance to help participants share their unique perspectives in a way that goes beyond the boundaries of conventional science-based methods. ABR could help explore moral injury and testimonial injustice in healthcare professionals and learners. Arts-based approaches have been used in mental health research to enable participants to communicate experiences of trauma or stigma through visual or narrative forms, which in turn have informed service redesign and clinician training. Such approaches demonstrate how incorporating lived experience can directly influence care pathways and improve responsiveness to patient needs.

These creative approaches also promote participant well-being as they provide an opportunity for self-expression and emotional expression. This therapeutic aspect of ABR can be particularly beneficial in health research where participants often experience difficult or traumatic experiences directly or indirectly related to their health issues or in the delivery of care.

PUBLICATION OF CREATIVE AND LIVED EXPERIENCE RESEARCH

One of the significant challenges faced by researchers working with creative methods and exploring lived experiences is the process of publication. Medical and health journals have vast experience with quantitative methodologies, often with limited cross-sectoral collaboration and sharing, and less familiarity with creative or qualitative methods, making it difficult for studies that use the latter to find a place in these journals.² However, this is gradually changing as the demand for more inclusive, holistic patient-led research grows²⁸ and more intersectoral

collaboration builds on known strengths beyond science-driven methodologies.²⁸

Several journals, including BMJ Leader Journal, are beginning to embrace the value of creative research methods and qualitative studies, recognising their potential to provide new insights into health and social care. This includes publications that focus on narrative research, ABR, and participatory research, as well as art and creative works as a way of storytelling, offering a platform for scholars to share their findings and push the boundaries of traditional academic publishing.²⁹ There are journals that are specifically patient-focused (The Journal of Patient Experience (<https://us.sagepub.com/en-us/nam/journal-of-patient-experience/journal202526>) or Patient Experience Journal <https://pxjournal.org/>). For these creative studies to be taken seriously, however, there must be an ongoing shift in how different types of data or evidence are valued. A more inclusive definition of 'evidence' is necessary, one that considers the outcomes of clinical trials or systematic reviews and also the lived experiences of individuals, groups and communities, the story or narrative. This broader understanding acknowledges that knowledge is not only generated in laboratories and in academic institutions but also emerges from the everyday realities of those directly affected by or working/learning within health and social care systems.

Such a shift challenges traditional hierarchies of evidence, which often privilege quantitative data over qualitative insights and further above the singular story. To recognise data from all sources calls for a more pluralistic approach that values narrative, artistic expression and co-produced knowledge, ultimately a way to elevate voices that have been less heard and meet the calls for social justice. This shift will not only enrich the evidence base but also help to create more equitable and relationship-centred care²⁹ and education systems. By legitimising diverse forms of data, we can better address health disparities, foster trust among systematically excluded populations and co-design interventions that are more responsive to the complexities of real-world contexts.

WHAT MEDICAL AND HEALTH JOURNALS CAN DO TO ADVANCE SOCIAL JUSTICE IN PUBLISHING

As discussed in this commentary, there is growing demand for social justice in academic publishing in healthcare through a number of lenses and calls on publishers to adapt. We explored the expansion of research methods to include more diverse and creative methodologies, inclusion of patient, care partner and community voices and how funding plays a role. To support these shifts towards more equitable and diverse publishing, journals must adopt flexible policies. Below are key steps from various discussions and consultations, including a BMJ Leader roundtable with patient experience journal experts that all publishers can use to better support, value and publish all forms of evidence.

Drawing on these considerations, we propose a set of practical actions that journals can take to advance social justice in healthcare publishing (table 1). Collectively, these actions move beyond inclusion as a procedural requirement towards a more fundamental rebalancing of power in knowledge production.

CONCLUSION

Advancing social justice in healthcare publishing requires more than a shift in editorial policy; it calls for a fundamental reimagining of what counts as knowledge, who generates it and how it is shared.³⁰ As research increasingly embraces creative, participatory and lived experience methodologies, journals, funders and

Table 1 Advancing social justice in healthcare publishing: actions for journals

Domain	Recommended actions for journals
Redefining Evidence	Broaden definitions of evidence to include qualitative, participatory and arts-based methodologies alongside quantitative approaches. Recognise lived experience, narrative and creative outputs as legitimate forms of knowledge that can complement traditional data.
Guidance for Creative and Arts-Based Submissions	Develop clear submission and reporting guidelines for creative and arts-based research that maintain academic rigour while respecting interpretive and subjective forms of knowledge.
Dedicated Spaces for Diverse Methodologies	Establish dedicated sections or article types for qualitative, participatory, lived-experience and creative research to increase visibility, legitimacy and accessibility.
Interdisciplinary and Cross-Sector Collaboration	Encourage collaboration across health, social sciences and the arts, including the meaningful involvement of patients, care partners and communities as contributors and co-authors.
Participation in Editorial and Review Processes	Include patients, care partners and community members in editorial boards, peer review and decision-making processes, with appropriate support and recognition.
Reviewer Capacity and Training	Expand reviewer pools to include expertise in qualitative, participatory and arts-based methods. Provide training and guidance to ensure rigorous and fair evaluation of diverse methodologies.
Valuing Patient- and Relationship-Centred Research	Prioritise research that captures relational, emotional and social dimensions of care, recognising their importance in improving patient outcomes and system performance.
Integrating Narrative and Storytelling	Create space for narrative forms, including patient, caregiver and practitioner perspectives, to complement empirical research and enhance contextual understanding.
Addressing Structural Inequities in Publishing	Prioritise research that addresses health inequities and includes systematically excluded populations. Consider equity in authorship, review and editorial representation.
Positionality and Reflexivity	Encourage authors to reflect on and report how their positionality influences research design, interpretation and knowledge production, particularly in studies involving marginalised communities.
Collaboration with Funders and Institutions	Work with research funders and institutions to align expectations, address structural barriers and promote equitable research and publishing practices.

ABR, arts-based research; BMJ, British Medical Journal; BMJL, BMJ Leader; NIHR, National Institute for Health and Care Research; PPI, patient and public involvement; RCT, randomised controlled trial.

institutions must evolve to recognise the value of these diverse forms of evidence.³¹

By expanding definitions of rigour and evidence, supporting interdisciplinary and community collaboration and embedding patient and care partner voices at every stage, from authorship to review, health journals can help dismantle long-standing inequities in knowledge production. This transformation will not only enrich the evidence base but also foster more inclusive, compassionate and relationship-centred care. Importantly, advancing social justice in research and publishing is not solely a moral imperative. Evidence increasingly suggests that more inclusive and contextually grounded research improves care quality, enhances patient safety, strengthens system efficiency and builds trust in healthcare systems, particularly among populations historically underserved or excluded.

BMJ Leader and like-minded publications are well-positioned to lead this change by modelling equitable publishing practices, creating space for creative and narrative forms of inquiry and amplifying the voices of those too often unheard in traditional research.¹⁴ In doing so, the publishing community can play a

pivotal role in shaping a future where health research truly reflects and serves the diversity of lived experience, and, ultimately, advances social justice across all systems of care.²⁷

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