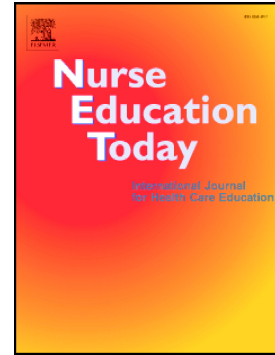


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Whose knowledge is of value? Co-designing healthcare education research with people with lived experience

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Whose knowledge is of value? Co-designing healthcare education research with people with lived experience.

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Introduction

“Co-design is more than a process. It is a social movement focused on challenging and changing inequitable power structures. Designing with, not for people.”

Kelly Ann McKercher

Whose knowledge is of value in healthcare education research? Despite advances in healthcare education – including creating rich opportunities for health professional learning and practice – healthcare education research (education research) still privileges the knowledge and expertise of clinicians, educators and researchers over that of healthcare consumers (Blinded, 2022). Hereto, healthcare consumers are referred to as people with lived experience (LE), by which we mean people with knowledge and wisdom gained through lived (and living) experience of a health condition, disability, circumstance (e.g. homelessness), or marginalised identity e.g., as defined by culture, race, gender, sexuality, class etc. Calls for ‘Nothing about us without us,’ originating from Consumer and Disability movements (Charlton, 1998), have prompted increased LE involvement in research co-design of health services and policy (Slattery et al, 2020) however the tertiary education sector has remained largely impervious to the benefits of community and LE participation in education research. Yet, as McMillan (2015) argues, the purpose of healthcare education research is to generate new educational knowledge in order to enhance healthcare practice and improve outcomes for people with LE. Therefore, the exclusion of people with LE begs the question, do we still ‘pick out the powerful and not necessarily what is the knowledgeable’ (Wylie, 2011), and thereby eschew the LE knowledge and expertise of those most impacted by healthcare education research? So, how might we begin to legitimize LE knowledge and expertise on healthcare research teams to ensure education research and related practice aligns with community and LE needs, values and expectations in healthcare?

Here, we, a diverse team of LE and health professional researchers, with expertise in education, research and healthcare practice, will critically examine the current lay of the land, before discussing the emergence of participatory approaches to co-designing education research with people with LE. We also discuss challenges and opportunities to co-design education research in tertiary settings, including highlighting longstanding insitutional barriers and practices that prevent the meaningful participation of people with LE.

The lay of the land in healthcare education research

Actively partnering with people with LE is a key priority in healthcare improvement, research and has recently been reflected in accreditation standards for health professions degrees. Privileging LE knowledge is essential for successful tertiary training of healthcare students in person centred and collaborative care that recognises people as experts in their own lives. The argument for active participation of people with LE in educational design and delivery has been made before. For example, Happell and Roper’s, (2009) pioneered dialogue around how to promote genuine LE participation, specific to mental health education; and *The 2015 Vancouver Statement* that set key priorities for embedding LE across health and social care education (Towle et al., 2015). However, to date, despite a recent review on the impact of co-production in nursing and midwifery education (O’connor et al., 2021), which identified positive impacts on knowledge, skills and learning, there is still a notable absence of collaboration with people with LE in healthcare education research.

Indeed, tertiary academic institutions and health professional governing bodies have traditionally emphasised health professional expertise, rather than LE expertise, in educational research, which originates, in part, in the training of health professionals that positions them more broadly as

‘experts’ in health. This has led to ‘norms of credibility’ that has kept people with LE on the periphery of healthcare education research and a refusal to acknowledge what Wylie (2011) refers to as the ‘epistemic authority’ of lived expertise. The question of epistemic disparity evokes Miranda Fricker’s (2007) term, ‘epistemic injustice’, which describes a situation whereby a perceived monopoly on knowledge by a dominant group (e.g. health experts) is prejudicial to the credibility of another ‘class’ of knowers (e.g. people with LE). In this epistemic territory, it is not surprising that people with LE have largely been excluded in healthcare education research, or alternatively their contribution – where it exists at all – remains ad hoc or tokenistic (Happell et al., 2015). The omission of LE epistemologies in education research has important implications. Epistemological assumptions not only influence education research design, they also impact on the kinds of conclusions that can be (and have been) drawn by healthcare educators that have downstream impacts on health professional practice (McMillan, 2015).

So, how can we disrupt the current status quo in healthcare education research and reframe LE expertise as a legitimate knowledge base in the production of education research evidence? In the following section, we present two substantive approaches to research co-design, undertaken in partnership with people with LE, that is expanding the epistemological landscape in healthcare education research.

Co-designing healthcare education research

Healthcare education and training is predominantly underpinned by Western, biomedical and reductionist framing of health and illness that negates the authentic and experiential knowledges derived from human experience. We believe critical research approaches like co-design are urgently needed to not only “understand and to disrupt notions of truth and the structures of power that have come to be taken for granted” in healthcare settings (Hodges, 2014, p. 1043), but also to widen healthcare education research knowledge and practice. We propose this starts with educators undertaking the important work of challenging presiding ‘knowledge’ in healthcare education through engaging in research co-designed approaches that value and legitimise LE knowledge and expertise. The term ‘co-design’ means different things across health and human services, and is often used interchangeably with other terms, including ‘co-production,’ ‘co-creation,’ and ‘personal and public involvement.’ In this paper, we distinguish a ‘substantive’ form of co-design research that incorporates elements of participatory action research (PAR), which emphasises critical inquiry equitable decision-making; and Scandinavian co-operative design, which incorporates creative design approaches that allow new forms of knowledge to surface (Langley et al., 2018). As a result, co-design research describes a *process*, a way of thinking and doing research (opposed to a single event) that is design oriented and intentionally democratic, whereby power and decision-making are shared, and processes are dialogical and transparent from the very beginning of the research process (Blinded, 2022). Here, we present two co-design research approaches that may help realign knowledge ownership in education research: *Depth of Field* and *Raising the Bar*. Both approaches are grounded in LE knowledges and driven by demands from Consumer movements, which is a vital, and often a missed step in producing humanistic healthcare education (Blinded, 2021).

In a program of research known as *Depth of Field*, Brand and colleagues (Blinded, 2021) found for LE knowledge and expertise to be embedded across healthcare education, there needs to be a collective commitment to expanding the epistemological landscape of healthcare educational research. In response, they describe five core principles for co-designing education research that is action and design oriented and undertaken in partnership with people with LE. First, being **inclusive** with people with LE and key stakeholders through all stages of the education research process, incorporating and evaluating creative design elements. Second, being **respectful** by equally valuing

LE input, including payment and co-authorship on scholarly outputs. Third, being **participative** through open, responsive and empathetic interactions that are key to generating new co-produced knowledge and understandings to inform healthcare education and practice. Fourth, ensuring an **iterative**, cyclic research process of exploration and reflection towards a collective education vision. Finally, being **outcomes focused** to achieve a final education research output that is not predetermined but co-created during the whole co-design process.

In a program of research known as *Raising the Bar*, a team of LE and academic researchers, including Bellingham, Kemp, River and colleagues (Blinded, 2021) found during co-design of health and education research, academics and clinicians tended to assume power rather than share power. This may be due to the lack of attention to power-differentials in co-design research, which commonly emphasises Scandinavian co-operative design principles over PAR methods. As a result, people with LE often experience powerlessness and silencing in co-design research teams, with their contribution reduced to that of a consultation. Therefore, they determined key requirements for disrupting and rebalancing academic and pedagogical power relationships and widen co-designed education research practices and, thereby, educators and students' views of health including: **Co-facilitated training** in co-design theory and practice for academics, clinicians and people with LE to support them to distinguish between consultation and co-design, and understand the potential for epistemic and power disparities. Co-facilitation with people with LE is required to embody and convey the value of partnership; **Praxis**, which involves opportunities for academics, clinicians, and people with LE to put theory into practice, by engaging in and reflecting on co-design education research under the guidance and mentorship of established co-design researchers; **Peer co-learning** for people with LE, which provides a deliberate space for solidarity, connection and peer learning to support people with LE to navigate power disparities and connect with the collective knowledge and expertise within Consumer movements to ensure co-design research initiatives are accountable to people with LE with diverse healthcare experiences and social backgrounds; and finally, **shifting social practice**, which includes recognising the systemic barriers that create practices of exclusion of LE knowledges in healthcare education research, and responding to these challenges by providing the necessary conditions for co-design research to thrive.

The aims of co-design education research partnerships, as we describe it, is to meaningfully partner with people with LE to ensure we are preparing healthcare educators and the future health workforce to reflect the needs and priorities of people who are most impacted by healthcare. As LE researchers on this paper have previously noted, co-design education research has profound impacts. It not only disrupts usual ways of knowing and doing in the academy, moving towards more inclusive practice, it also supports LE and health professional educators to embody and convey the possibility of partnership to healthcare students (Blinded, 2021; Blinded, 2022).

Opportunities and challenges to research co-design in tertiary education settings.

Despite powerful learning opportunities resulting from co-designed education research, there are also some key challenges for meaningful research co-design relating to knowledge, relational and systemic factors. In terms of knowledge, academics and educators may have deficits in understanding levels of participation and key differences between consultation, where a person or group of people are heard without any guarantee of influence, and co-design, which involves working in research partnership in the co-planning, co-design, co-delivery and co-evaluation of an education initiative (Blinded, 2022). Targeted training could provide opportunities for developing knowledge about research participation, as well as deeper understandings of the epistemic disparities in healthcare education research. Increased knowledge might support a collective commitment to recognising and devolving power and using one's position to promote perspectives of people with

LE, who may feel reluctant to share what they really think would be useful in healthcare education research (Blinded, 2021). This leads to relational considerations that are inherent in co-design research processes that involves sharing power and decision making in respectful and reciprocal ways. For example, people with LE may disrupt usual ways of knowing and doing in healthcare education research which might be experienced as challenging to academics and educators. Rather than resisting this disruption, we need to see it as a growth opportunity for expanding the epistemological lens in healthcare education research, including reframing it as generative experience (Blinded, 2022). It is in diverse perspectives that innovation is born, and with careful attention to power, and deliberate checking in around decisions, authentic co-design is made possible in healthcare education research.

Finally, systemic factors, including longstanding educational institutional barriers can hinder co-design in healthcare education research. For example, tertiary sectors often insist on standard academic credentials (e.g. Masters level qualification) or offer tokenistic payment, a voucher or gift card for people with LE who partner in co-designing education research. This is despite key stakeholders recommending equitable payment that aligns with how others are paid for working on the same or similar projects, including being paid ‘at the same rate as any other academic’ and opportunities for ongoing LE employment (Horgan et al., 2019, p. 559). We argue that fair pay could be achieved through allocating funding monies to LE members on research teams, as well as through the establishment of substantive and continuing LE academic positions in health and medical faculties (Dorozenko et al., 2016). These changes would not only ensure sustainability of co-designed education research - as people with LE feel respected and are more willing to return for further co-design research projects— it is also vital for avoiding stigma and discriminatory practices against those with LE who are often living with a physical or psychosocial disability. Finally, while speedy deliverables might suit organisational purposes, realistic and sufficient timeframes are needed to engage in the iterative and democratic deliberation that lies at the heart and ethos of research co-design processes.

Conclusion

In order to expand the epistemological landscape in healthcare education research, we need to value the powerful knowledge and expertise people with LE bring. As Indigo Daya, an Expert by Experience and LE academic states, *“People want to have a say about the things that affect their lives. The bigger the impact, the more say we want.”* However, for this to be achieved, we need to address longstanding educational institutional barriers and practices that have prevented the meaningful participation of people with LE in healthcare education research. In our critical work, we found co-designed education research with people with LE has the power to disrupt and rebalance traditional, academic and pedagogical power relationships that widens healthcare education research practices through realigning knowledge ownership, with associated benefits for healthcare educators and students.

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