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Title

The Social Organization of Patient Engagement: An Institutional Ethnography (IE) Study

Priority 1 (Research Category)

Patient engagement

Presenters

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Abstract

Patient engagement (PE) in research is intended to be a “meaningful collaboration” with patients as partners in all aspects of research (CIHR, 2019). The purpose of PE is to engage people with lived experience of a health condition to integrate into research projects what they deem valuable. Through PE, the hope is that subjugated perspectives are being brought forward. However, no universally accepted framework for including voice, perspective, knowledge, and experience in PE exists (Domecq et al., 2014). Indeed, there is significant variation in how PE is defined and practiced, alongside an inadequate representation of systemically and structurally marginalized populations such as migrant populations, those living in poverty, people with mental illnesses, people who use drugs, and racialized groups (Brown Speights et al., 2017; Tremblay et al., 2020). The experiences of many people living with chronic pain in Canada are exemplary of the kinds of marginalization, exclusion, and depoliticization that necessitate effective ParE. Affecting one in four Canadians over the age of 15 (Campbell et al., 2020, p. 5), chronic pain is a stigmatized health condition within medicine due to its subjective nature. We conducted an institutional ethnography (IE) of ParE that began from the standpoint of people with lived experience of chronic pain and marginalization in order to begin identifying the institutional interests underpinning pain research in Canada. In keeping with our commitment to social justice, our core research team was comprised of three senior investigators experienced in IE, two trainees, and two people with lived experience of chronic pain and marginalization. Drawing on our findings, we discuss how a meaningful shift in conceptualization and practice yields a potential to reframe how certain conditions/diseases are normatively understood, thereby leading to the democratization of research and health for the benefit of people living with chronic pain and marginalization. We highlight how equity, diversity, and inclusion can be applied to ParE; the need to revise existing methodologies; and expanding notions of “who counts” in pain research.