Submission Id: 5445

Title

Democratizing Participant Engagement of Marginalized Communities in Chronic Pain Research: Crafting a Way Forward

Priority 1 (Research Category)

Patient engagement

Presenters

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Abstract

Increasingly, the value of meaningful collaboration with people with lived experiences of inequities is being recognized by researchers and funding bodies; we refer to this as Participant Engagement (ParE). There is currently no universally accepted framework for ParE and collaboration often excludes structurally marginalized populations despite the prevalence of chronic disease in these communities. This presentation aims to identify how we can draw on critical social science approaches to modify conceptualizations of engagement to better reflect the needs and knowledge of those living with chronic pain who have been marginalized by structural oppression and shift our focus from individuals to communities. The multi-disciplinary speakers of this symposium, who are senior, mid-career, and trainee researchers, will call attention to how the quality of chronic pain research can be enhanced and contribute to social and health equity in policy and care. Our team are members of a national Partnership supported by the Social Science and Humanities Research Council (SSHRC) in Canada to explore this issue (PEPR). We will 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. Participants will be offered an opportunity to build their knowledge and critical thinking through a sustained and sequential focus on various aspects of this topic: equity, diversity, and inclusion as applied to ParE; a historical and sociological overview of patient engagement; the need to revise existing methodologies; and expanding notions of “who counts”.