

‘What Do I Ask and Who Do I Ask?’: Exploring the role of evidence-informed advocacy for individuals living with a chronic illness

Tuesday, July 16, 2024 3:40 PM (20 minutes)

Engaging knowledge-users within an integrated knowledge translation (iKT) research process enhances the relevance of research outputs and outcomes. During the COVID-19 pandemic, our research team surveyed an international sample (n=1,090) of lupus (a chronic autoimmune condition) patients to increase understanding of how they access and trust health information. While lupus specialists and family physicians were ranked as most trustworthy, participants accessed these sources less frequently during the pandemic. Advocacy organizations, an accessible and credible source of information, were accessed less frequently compared with lupus specialists, family physicians and news and social media (less trusted sources), and trust in advocacy organizations decreased during the pandemic. To further explore these results, we used an iKT approach in partnership with Lupus Canada to engage Canadians with lupus to elicit their perspectives on the survey results and explore the role of advocacy organizations in meeting the information needs of individuals with lupus. Semi-structured in-depth interviews (n=16) were conducted in March/April 2023; preliminary results suggest that participants report a critical need for credible lupus-related information. Although the sample was recruited through Lupus Canada’s newsletter/social media, participants report a lack of awareness of advocacy organizations and that they primarily access other sources (e.g., physicians) for health information. Identified factors that influence trust in advocacy organizations include content that is perceived as overly general, and the perception that they are associated with government/are financially motivated. Lupus Canada will use the results of this work to support information development and dissemination for those living with lupus in Canada.

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Session Classification: Paper Presentations

Track Classification: Health, Justice, Human Rights, Policy & Practice: Health Disparities