

NAPCRG 52nd Annual Meeting — Abstracts of Completed Research 2024.

Submission Id: 6557

Title

Why do patient/caregiver partners feel like outsiders ? The research workplace culture as a deterrent to true partnership.

Priority 1 (Research Category)

Patient engagement

Presenters

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Abstract

Context: The Patient Advisors Network (PAN), was asked by the Canadian Institute for Health Research (CIHR) to contribute insights from the unique perspective of patient and caregiver partners to the Strategy for Patient-Oriented Research (SPOR) Refresh process. PAN conducted a survey and two focus groups generating a wealth of data supporting the inquiry and analysis. PAN is a Canadian independent community of patient/caregiver partners who led the study through all phases.

Objective: To gather insights from PAN members as well as the wider patient/caregiver partner community to learn of their experiences as partners in health research, to inform the Refresh process

Study Design and Analysis: PAN conducted a survey with 262 Canadian respondents, covering every province plus the Northwest Territories and held two focus groups of 15 people. All aspects of this work were led and conducted by patient/caregiver partners.

Setting : The survey and focus groups were conducted with people from across Canada.

Population Studied: Patient/caregiver partners (people with lived and living experience) who had experience as partners in health research or were interested in becoming involved.

Instrument: Results and suggestions were documented in a Report to CIHR and shared with research and patient/caregiver partner communities and networks

Outcome Measures: Actionable suggestions on how to Improve patient/caregiver experiences in research.

Results – Analysis of the data highlighted a range of examples which collectively captured the experience of patient and caregiver partners feeling like outsiders. Taken together these are described as an unconscious cultural lens , part of the research workplace . These findings suggest this may be a deterrent to equitable partnerships when engaging patient/caregiver partners.

Conclusions: This study will inform CIHR's SPOR refresh plans and will help researchers, patients and decision makers interested in advancing patient partnerships in the broader health care ecosystem. The findings indicate further examination of the cultural lens is warranted.

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