Perspectives of Patients as Partners in the ICDC Innovative Clinical Trials

E.Benterud[1], P.Amin-Javaheri[1], J.Babione[1], D.Campbell[1], K.Dhaliwal[1], P.Edgar[2], M.Graham[2], D.Kruger[1], N.Pannu[2], W.Pearson[1], S.Robertshaw[1], T.Sajobi[1], R.Tsuyuki[2], N.Verdin[1], K.Watson[2], P.Wiebe[1], S.Wilton[1], M. James[1].University of Calgary,[2]University of Alberta

BACKGROUND: Traditionally, patient contributions have been limited to the role of participants. This program allows patient partners to inform the design of innovative trials

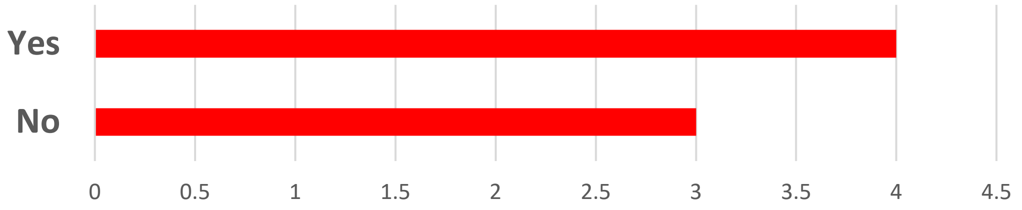
PURPOSE: Present feedback from annual partner surveys

RESULTS: Engaged 6 patient partners with lived experience. They meet regularly with the research team to set priorities and provide guidance. Overall, the partners express a high degree of chronic disease participation

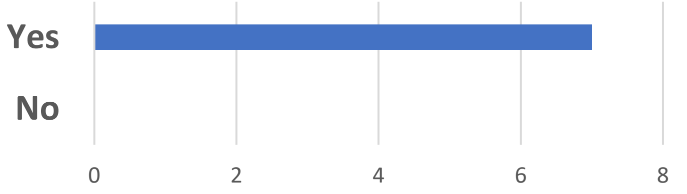
EDI: To keep research patient centered, relevant and useful; teams need to establish trust, a sense of legitimacy in research roles and responsibilities, and to encourage successful uptake and use of research results

CONCLUSION: Connecting patients and researchers is important to cultivate the culture that is patient centered

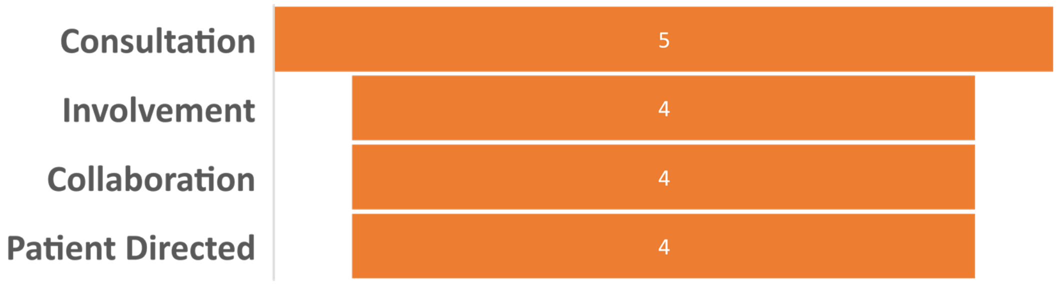
Does or would having more than 1 partner make it easier for you to speak up?



Do you feel the team listens to you and absorbs your input?



What level of engagement do you have on the team?



What could the research team do to improve your experience?

"Put us on the agenda for feedback"

" Ask me more questions"

"I am eager to add any value I can"

" most common problem is I am left as an observer"

"Try to provide an update on what is happening behind the scenes"

UNIVERSITY OF CALGARY

UNIVERSITY OF ALBERTA

Eleanor.Benterud@ucalgary.ca

SPOR004