International Journal of Population Data Science

Journal Website: www.ijpds.org

Identifying superusers of health services with mental health and addiction problems: Putting the Canadian Institutes of Health Research Strategy for Patient Oriented Research into action

Quail, Jacqueline^{1*}, Schaefer, Joelle¹, Neudorf, Cory², Anderson, Maureen², McLeod, Valerie³, Lafontaine, Tania³, Pelly, Judy³, Pruden Nansel, Kathie⁴, Baetz, Marilyn⁵, Baker, Margaret⁶, Teare, Gary¹, and Muhajarine, Nazeem⁷

¹Health Quality Council (Saskatchewan)

²Saskatoon Public Health Observatory, Saskatoon Health Region

³First Nations and Metis Health Services, Saskatoon Health Region

⁴Citizen Researcher

⁵Dept of Psychiatry, University of Saskatchewan

⁶Saskatchewan Ministry of Health

⁷Dept of Community Health and Epidemiology, University of Saskatchewan

Objective

We were funded by Canadian Institutes of Health Research Strategy for Patient Oriented Research (CIHR-SPOR) to use administrative data to identify people with mental health and/or addiction (MHA) problems, and determine characteristics that lead to them becoming a superuser of health services. The aim of the CIHR-SPOR is to ensure that research improves healthcare systems and practices. Their approach is to fundamentally change the ivory tower nature of research to make it more inclusive, user friendly, and timely. An essential component of the CIHR-SPOR is engaging patients as partners at all stages of the research. In this presentation we will describe the challenges, successes, and failures of engaging patients as part of the research team.

Approach

In Saskatchewan, Canada, we engaged with community programs to determine the 'on-the-ground' reality of people living with MHA problems. Our discussions revealed that First Nations and Métis People are highly overrepresented in the MHA patient population. For example, they comprise 15% of the Saskatchewan population yet 70% of patients receiving treatment at a local methadone clinic. For this reason, we are focusing our efforts on engaging with this specific patient population.

Results

We encountered a number of barriers to finding patient advisors. First, patient advisors available through institutional programs are not representative of our target population, being more affluent, well-educated, and Caucasian. There are currently no formal avenues to identify and invite members of the target population to join the research team and so we are using personal connections and team building to identify patients advisors. Second, complicated institutional policies on reimbursement for patient advisors impede participation by low income individuals. Third, we are concerned the socioeconomic disparities common in this vulnerable population may impede their full and honest participation as a patient advisor.

Conclusion

Patients and their family members are invaluable members of the research team. However, a power differential often exists between team members and patients due to socioeconomic differences, including race and education. Stigmatized health conditions such as MHA problems can exacerbate the feelings of a power differential. All of these things can prevent genuine involvement by patients. The most important step in successfully involving these untraditional team members is building trust through unconditional acceptance and respect for each individual's lived experience. Building trust takes time and so patient engagement cannot be expected to follow a rigid schedule.

*Corresponding Author:

Email Address: jacqueline.quail@gmail.com (J. Quail)