

Patient Engagement in Research Community of Practice

March 2023: Engagement in Diabetes Research

This document provides a presentation summary on the importance of engaging people with lived experience in research to reduce barriers to screening for diabetic retinopathy.

Key Presentation Points

- Diabetes Action Canada (DAC) is a national diabetes research network spanning 8 provinces, 120
 researchers, 10 programs, 29 partners, and over 200 patient partners. DAC is funded by the Canadian
 Institutes of Health Research (CIHR) and other funding partners.
- Project OPEN has engaged people living with or affected by diabetic retinopathy from start to finish.
 Project OPEN focuses on improving access to screening to underserved communities living with or at risk of developing diabetic retinopathy.
- It can be challenging to identify or contact people with diabetes to complete diabetic retinopathy screening. One well-received strategy has been the use of existing data to contact people.

What did we discuss?

- Onboarding, training, and ongoing education: It is helpful to provide onboarding, training and education to patient partners. This can help patient partners' to feel confident, prepared, and equipped to meaningfully collaborate and contribute. Strategies that engage patient partners should include ongoing training and support as well as adequate orientation during onboarding.
- **Challenges:** Co-applicant or co-principal applicant credential and training requirements pose challenges to engagement.

Relevant Resources on Patient Engagement in Research

- <u>Diabetes Action Canada patient engagement webpage</u>: A webpage with resources, information, and opportunities about the engagement of patients, family members, and care partners in diabetes research.
- <u>Diabetes Action Canada website</u>: A website with information and resources about diabetes research within Canada.







