

A patient-initiated research project to improve diabetes management and care.



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**Engagement of Those with Diabetes
to Envision our Future
2020 DAC Summer e-meeting**

Introduction

- **People living with diabetes have unique and valuable expertise of diabetes management and care.**
- Patients partners can help:
 - other people living with diabetes to improve self-management and,
 - health professionals to provide more patient-centered care.

Phase 1

- **Objective:**
 - Describe patients' knowledge about how to live well with diabetes
 - Identify how health professionals could provide better diabetes care

Phase 1

- **Data collection:**
 - 21 diverse men and women living with diabetes (type 1, type 2 and pre-diabetes), including caring for people with diabetes
 - Video interviews



Patients interviews – Phase 1

- (a) What makes you feel healthy?
- (b) What knowledge, wisdom or advice do you want to share with other patients about how to live well with diabetes?
- (c) What knowledge, wisdom or advice do you want to share with health professionals caring for people living with diabetes to help them provide better care?

Highlights – Phase 1

- **Results:**
 - Communication is important
 - Holistic approach is needed
 - Cultural safety and social support are crucial
- **Tools:** Patient-led learning modules about how clinicians can better engage patients in medical care

Publication- Phase 1

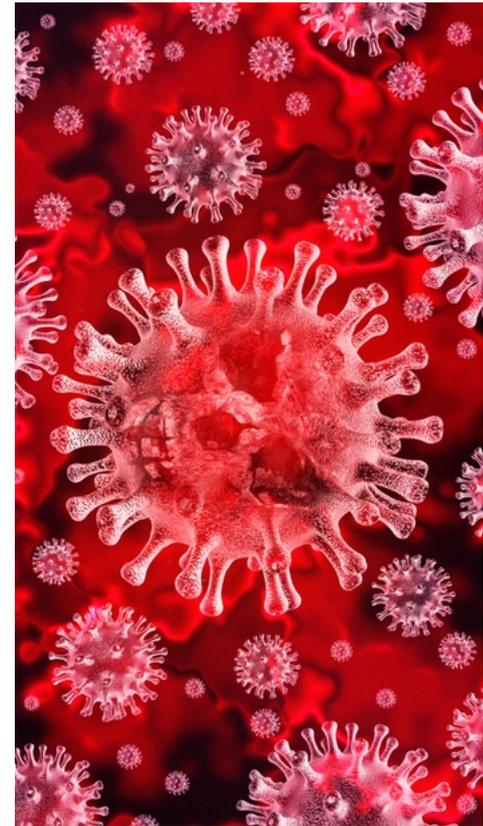
- **Who:** Ndjaboue R, Chipenda Dansokho S, Boudreault B, Tremblay MC, Dogba MJ, **Price R, Delgado P, McComber AM**, Drescher O, McGavock J, Witteman HO (2020).
- **What:** Patients' perspectives on how to improve diabetes care and self-management: qualitative study.
- **Where:** *BMJ Open*. 10:e032762. PMID : 32354775

Phase 2

- **Objective:** To evaluate patient-led learning video modules on patients' knowledge and emotions and on future health professionals' knowledge and empathy
- **Methods:**
 - 30 participants (health professional trainees and patients)
 - Human-computer interaction measures (e.g. eye tracking, skin capter) and self-report questionnaire

COVID-19 impact – Phase 2

Lab studies interrupted



Phase 3

- **Objective:** To determine whether patient-led videos change medical students' 1) responses to clinical scenarios and 2) sense of importance of medical competencies?

Phase 3

- **Methods:**
 - **Design:** Randomized, within subjects, pre-post pilot study
 - All medical students saw same videos
 - Randomized to answer questions about importance of different competencies before or after videos

Phase 3

- **Methods:**
 - **Design:** Randomized, within-subjects, pre-post pilot study
 - 3 pairs of clinical scenarios = 6 scenarios total
 - 2 scenarios focused on addressing patients' emotions
 - 2 scenarios on cultural safety
 - 2 scenarios on patients requesting a prescription/referral
 - One scenario in each pair was T1D, the other T2D
 - Students answered 1 scenario chosen randomly from each pair before watching the videos; the other after

Phase 3

- **Methods:**
 - **Population:** ~ 220 eligible participants
 - Medical students enrolled in 2nd/3rd year course at Université Laval
 - Optional activity at end of course
 - Hoped for ~20-80 participants
 - **Data collection:** Online survey (questionnaire and scenarios)

Example of scenario – Phase 3

- *Mrs N. aged 48 years old has a 16-year-old daughter newly diagnosed with type 1 diabetes. You encounter them for the first time. Blood glucose test results in the last two weeks were often higher than target values.*

Example of scenario – Phase 3

- History:

Diagnosed with type 1 diabetes 4 months ago.

Weight 49 kg, height 155 cm

Lab results of the previous week show acceptable figures; including HbA1c 7.1% (54 mmol/mol) and a random blood glucose of 4.0 mmol/L. No family history of diabetes of either type.

Example of scenario – Phase 3

- Reasons for the visit:

Mrs. N. wants your opinion regarding her daughter's ability to participate in Ramadan. Ramadan is a religious requirement for people observing Islamic law which requires 40 consecutive days of food deprivation. As usual, the whole family is preparing for Ramadan by gradually reducing nutrient intake. Starting the next day, everyone participating must fast on an empty stomach from sunrise to sunset for 40 days.

Describe your attitude, what you will say and do.

Roles evaluation – Phase 3

- *Among the different roles of health professionals below, what importance do you place on each of them to provide high quality care to people living with diabetes?*
- *Rank from 1 (Not important at all) to 10 (Extremely important)*

Preliminary results – Phase 3

- **Sample size:**
 - Before-video group: n=15
 - After-video group: n=10
- **Quantitative data:**
 - Competencies scores (1-10 scale)
- **Qualitative data (analyses in progress):**
 - Responses to scenarios
 - Feedback on video

Preliminary results – Phase 3

Table 1: Importance of CanMEDS Roles from medical students' perspectives

Medical competencies	Before video Mean scores (/10)	After video Mean scores (/10)
Communicator	9.2	9.1
Collaborator	9	8.9
Scholar	8.3	7.5
Manager	7.5	7.1
Professional	8.9	7.9
Health advocate	8.9	8.8

Discussion – Phase 3

- Highest scores attributed to communication
→ it is central to patient-centered care
- No great differences between mean scores
→ roles are interrelated
- Lower mean scores of scholar and professional roles in After-video group → listening to patients' perspectives of diabetes care may mitigate the importance of academia-related roles compared to behavioral-related roles

Next steps – Phase 3

- Evaluate trainees qualitative responses
- Refine learning modules videos according to trainees feedback
- Run another intervention using revised materials (6-month follow-up)
- Evaluate the effects of the upcoming intervention
- Share patients' perspectives and results through relevant networks

Patient Partners' involvement

- Research questions informed by lived experience of patients
- Video interviews from patients
- Modules creation revised by patients
- Manuscript writing using priorities and/or preferences of patients
- Knowledge translation planned with patients

Lessons learned

- Acknowledge patients' burden from diabetes and research
 - Allow patients to withdraw
 - Adapt language and presentation (e.g., allow oral versus written feedback)
 - Reinvent studies and patients' involvement during crisis
- Tailoring most if not all strategies and tools to patients have reinforced capacity building in our patient-oriented project**

Thank you

