


# Research Partnerships with Patients Living with Type 2 Diabetes: Practices and Challenges in Quebec Among People New to Canada

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## Les partenariats de recherche avec les patients vivant avec le diabète de type 2 : Pratiques et enjeux chez de nouveaux arrivants au Canada résidant au Québec

Séraphin Balla<sup>1</sup> , Maman Joyce Dogba<sup>2</sup>, and Monika Kastner<sup>3</sup>

### Abstract

Patients are increasingly encouraged to participate in health research programs as partners, with the aim to ensure that studies address their priorities. In response, the Strategy for Patient-Oriented Research (SPOR) has been created in Canada to transform the patient's role in research from a passive beneficiary to a more proactive partner of change within the healthcare system. This research investigates what people new to Canada living with type 2 diabetes think about participating in research partnerships. Using an ethnographic approach, 31 people new to Canada with a diagnosis of type 2 diabetes were interviewed. Findings indicated that few people new to Canada were represented among the Diabetes Action Canada (DAC) Network's Circles of Patient Partners in Quebec. Barriers to engagement in research were: lack of information; competing priorities; language barrier and privacy concerns; preconceptions about being a patient partner; prejudices on research engagement as something demanding and binding; and the matter of religious and gender differences. Some participants questioned the extent to which involvement in research can really meet their expectations considering institutional control over research, funding requirements that often dictate priorities and the biomedical approach which still, in many respects, dominates health research. Implications for achieving equity, diversity, and inclusion of patient partners in research are discussed.

### Keywords

patient-oriented research, patient-partner, research partnerships, immigrants, health equity, diabetes, Canada

### Résumé

Les patients sont de plus en plus encouragés à devenir des partenaires de recherche en santé afin que leurs besoins soient mieux pris en compte. C'est dans cette optique que la Stratégie de Recherche Axée sur le Patient a été créée au Canada, pour que le patient soit plus qu'un bénéficiaire passif des soins et devienne un acteur proactif du changement au sein du système de santé. Grâce à une approche ethnographique, cette recherche examine comment 31 personnes vivant avec le diabète de type 2, qui résident au Québec et qui sont nouvellement arrivées au Canada apprécient l'engagement dans des partenariats de recherche. Les résultats font constater que les personnes nouvellement arrivées au Canada sont sous-représentées dans les Cercles de patients partenaires du réseau Action Diabète Canada (ADC). Les barrières identifiées sont liées : au manque d'information, aux conflits d'horaire, aux barrières linguistiques qui soulèvent aussi les problèmes de confidentialité, aux idées préconçues sur le rôle du patient partenaire, aux perceptions suspicieuses de la recherche ainsi qu'aux différences religieuses et de genre. Par ailleurs, les personnes interrogées se demandent à quel point leurs points de vue peuvent vraiment changer quelque chose, étant donné que les recherches font l'objet d'un contrôle institutionnel, que les opportunités de financement dictent les priorités de recherche et que l'approche biomédicale est omniprésente dans les sciences de la santé. Pour conclure, l'article souligne que l'implication de patients partenaires dans la recherche soulève des enjeux d'équité, de diversité et d'inclusion.

### Mots-clés

recherche axée sur le patient, patient partenaire, partenariats de recherche, immigrants, équité en santé, diabète, Canada

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## Introduction

Different models of participation are now encouraged in health research, all advocating the engagement of patients, members of the public, and other service users throughout the research process (Abma et al., 2019; E. Wilson et al., 2018). It is assumed that patients are not merely “research objects,” but could be partners (Lechner, 2013), because of their experiential knowledge. Their involvement in research should not only acknowledge their participation, but also allow the co-creation of knowledge (Abma et al., 2019). In Canada, the Strategy for Patient-Oriented Research (SPOR), as promoted by the Canadian Institutes of Health Research (CIHR), is dedicated to this objective aimed at moving patients away from being passive users of health services to becoming active and engaged research partners to improve treatment and care services. This implies meaningful collaboration of patient partners throughout the research process, from its conceptualization to the translation of the results into clinical practice (Canadian Institutes of Health Research [CIHR], 2019). Therefore, there is a genuine concern for the inclusion of multiple perspectives in the research process, no longer reserved just for academic and clinical stakeholders (Harrison & Brooks, 2015; Park, 2006; Rolfe, 2000). This means that each patient should be allowed to share his or her lived experience (Shannon & Hambacher, 2014). In the same vein, multidisciplinary approaches have acquired greater importance to address political, cultural, and socioeconomic issues which surround health problems. However, there is a growing body of multidisciplinary literature which highlights some limitations and challenges to models of participatory and collaborative research with patient partners (Wiggins & Wilbanks, 2019; E. Wilson et al., 2018), especially with immigrants and minorities. In Canada, the word “immigrant” is often used to designate any person born outside the country, even if he/she has acquired permanent residence or citizen status. However, since 2001, Canadian immigration legislation no longer uses this term to designate permanent residents or citizens. Therefore, some citizens or permanent residents do not appreciate being considered as immigrants or new to Canada, even if they continue to identify themselves with their native country, or with their cultural group. Therefore, there is a negative connotation to having an immigrant or new to Canada status, and perceived as derogatory by some people, even if we cannot consider this to be a commonly shared view. Within partnerships, it is important to acknowledge that patients might consider this label as stigmatizing, as though they were still

classified as foreigners. As such, it may be important to clarify these terms in any given research project. In our study, we therefore consider “immigrants,” the individuals who were not born Canadians, but have a legal status as citizens or permanent residents, self-identify as immigrants, and also identify with a given cultural group. However, I refer to the term “immigrants” as “new to Canada” and “racialized populations” throughout the manuscript to promote more inclusive language.

Indeed, there has been several challenges identified with the SPOR, one of which is to be more inclusive and sensitive to the Canadian multicultural context. Another challenge is to consider health problems that are specific to people new to Canada as well as racialized populations living with diabetes. Addressing these gaps is the mission and dedicated component of the Diabetes Action Canada (DAC) Network. The DAC Network is a Pan-Canadian catalyst research consortium focused on scaling-up effective healthcare solutions that directly improve outcomes for people living with diabetes and its related complications. Their SPOR Network in chronic disease consists of a diverse team of patient partners, researchers, diabetes specialists, primary care practitioners, nurses, pharmacists, data specialists, and health policy experts committed to improving the lives of persons living with diabetes. The DAC Network has a Circle of Patient Partners composed of Francophones and people new to Canada. However, few people new to Canada are represented within the patient circles of the DAC Network, yet type 2 diabetes is endemic among them (Public Health Agency of Canada [PHAC], 2011) (Battaglini et al., 2014; Creatore et al., 2012; Newbold & Danforth, 2003). Although the Network attempts to resolve the low representation of people new to Canada in its research partnerships, it is not clear whether these partnerships are relevant for them or address their expectations which are not always clinical. In addition, integrating people new to Canada in research means being able to address their differing needs across a wide range of factors such as gender, race, religion, language, skills, etc. (Hamelin et al., 2018); so, are researchers and stakeholders prepared to respond to these complexities and challenges? These are the questions that we address in this article using ethnographic data collected from people new to Canada living with type 2 diabetes in Quebec, Canada. The aim of our study is to highlight what, from their opinions, perceptions, and social contexts, may be barriers to their engagement in research partnerships.

<sup>1</sup>Université Laval, Québec, QC, Canada

<sup>2</sup>Department of Family and Emergency Medicine, Université Laval, Québec, QC, Canada

<sup>3</sup>St. Michael's Hospital, University of Toronto, USA

\*Séraphin Balla is also affiliated to Department of Anthropology, University of Yaounde I, Yaounde, Cameroon and Monika Kastner is now affiliated to North York General Hospital, Toronto, ON, Canada

### Corresponding Author:

Séraphin Balla, Université Laval, 110 Rue du Temple, Québec, QC G1E 5A5, Canada.

Email: seraphin-guy.balla-ndegue.1@ulaval.ca

## Background and Theoretical Framework

In our study, the concepts “participation” and “engagement” of people new to Canada in the health system are central and we approach them from the perspective of social and health sciences. Indeed, as Abma et al. (2019) explain, central to the emergence of the patients and the user involvement in research, is the growing acceptance that individuals are experts in their own bodies/experiences of health and illness. We used the SPOR as promoted by the CIHR to analyze how people new to Canada and living with type 2 diabetes perceive these concepts and related activities. Indeed, CIHR considers the SPOR (CIHR, 2019) as a set of scientific activities on humans, producing effective evidence-based results, and the integration thereof into the health system and clinical practices. The SPOR aims to address diminishing capacity of stakeholders to apply the results of biomedical research to benefit patients and the limited ability to integrate research findings into clinical practice. The SPOR has been designed to demonstrably improve patients’ lives by promoting the involvement of patients in research; as participants to generate data, as partners in steering research projects, and as experts in the lived experience of health conditions. The expectation of this level of involvement in research by patient partners is to increase the relevance of research findings through their experiential knowledge and public responses.

According to the CIHR, patient engagement in research is his/her meaningful and active collaboration in the governance, priority setting, research implementation, and the translation and dissemination of knowledge. With people new to Canada, the objective according to Robert et al. (2018, p. 313) could be “to listen to their voices, both in a perspective to better understanding their realities, to implement needs-oriented policies and services, and from an empowerment perspective.” For this purpose, the collaboration should lead to accountability and transparency, and it should provide new insights that can lead to innovative outcomes, as well as results that better meet patient needs. Several authors (Abma et al., 2019; Harang, 2006; Robert et al., 2018) argue that the participation implies the possibility for an individual to join, to take part, to feel involved, to contribute to the development and success of any activity. We are talking about engagement when the participation is no longer occasional or sporadic and when the individual, feeling responsible, binds himself by a decision for the different steps of the project. Research partnerships therefore do not mean occasional participation, but rather long-term engagement.

This nuance between the engagement and participation is not clearly distinguished by the SPOR. Even if the two concepts overlap, the engagement could, even to a lesser extent, have a moral connotation, as it is anchored in the values and beliefs of individuals, for one only defend the causes that correspond with our values (Harang, 2006). Indeed, engagement entails that an individual is aware of what he/she is

committing himself/herself to. It is evaluated over time and entails more than a one-time participation to achieve some change. By engaging in anything, individuals pledge their credibility and reliability, because the engagement requires respecting the terms and conditions. It is then morally binding.

However, there are linguistic, social, and cultural problems that people new to Canada face, which have an impact on their interest in research partnership. We used the SPOR program in Canada as a case study. Indeed, while SPOR admits that socio-cultural determinants of health are important, it fundamentally promotes clinical/biomedical health approach, “which heavily relies on statistics, harmonized protocols and standardized interventions” (Olivier de Sardan, 2017, p. 71). Yet, the same importance should be attached to the cultural and socioeconomic challenges faced by individuals new to Canada in order to improve their healthcare access and appropriate healthcare services. Our study also explored the meaning of “research” among people new to Canada, considering that they have different cultures, and levels of educational qualifications.

## Methods

We first conducted the literature review to better understand the area of participatory research, patient-oriented research, patient engagement and participation, health anthropology, research and ethics, health, immigrants, and migration. We used fieldwork ethnography as our methodology to collect empirical data through qualitative interviews and observations. These data allowed to highlight the perceptions and the meaning that patients new to Canada give to research partnerships, and what could be barriers to their engagement in research partnerships. As Olivier de Sardan (2017) points out, the fieldwork for collecting empirical data is the only solid basis for producing new knowledge and new interpretations of what social actors themselves think about their reality and context. Given the comprehensive aim of qualitative research, the context is as important as individuals’ point of view, because it is what changes the validity of a given proposition (the same proposition is true or false depending on the context) or the meaning of a given practice (the same practice takes on different meanings depending on the context) (Dumez, 2011; Rueff, 2015). Our research was approved by the Laval University Research Ethics Committee (2017-141/17-10-2017).

## Recruitment of Participants

This research was conducted between 2017 and 2018 in Quebec and Montreal. The data analysis continued until 2020. The main selection criterion of the participants was to be an adult (age  $\geq 18$ ) with type 2 diabetes, with or without experience participating in a research study, regardless of the period of arrival in Canada, but with legal status. The recruitment process began through the DAC’s Circle of Patient

Partners that we contacted through its coordinating officer at Laval University. Only four patient partners were members of the DAC Patient circle dedicated to people new to Canada. This indicates how underrepresented they are within the patient circle of the DAC network. Let us note that:

Each patient circle brings together a variety of people living with diabetes from all over Canada who share a common mission to promote patient-centered diabetes research and to help improving the quality of diabetes research and its complications. Patient circle members meet throughout the year to discuss different projects and put their expertise, as people who know what living with diabetes means, to the service of researchers and administrators. Partner patients also have the opportunity to become members of the research team. By talking about their experiences with diabetes, they help to ensure that science, publications, new projects and the communication of our research findings are more relevant and accessible to people living with diabetes. (Diabetes Action Canada, 2018, p. 5)

We then performed network and snowball sampling. This involved engaging with the four DAC Patient Partners who were new to Canada to iteratively recruit additional patients from their respective cultural community. Each consenting patient participant was then invited to disseminate the recruitment information within his/her network. We stopped recruiting participants when we reached saturation of themes (i.e., the interviews no longer provided new information in relation to the research topic). The saturation here means that with the sample recruited, we collected a reasonable range of data to address the aim of the study. However, we agree with Thorne (2020) that there is a wide range of possible experiences on every topic and the decision about when to stop data collection, are inescapably situated and subjective, and cannot be determined (wholly) in advance of analysis (Braun & Clarke, 2021).

### **Data Collection**

The qualitative interviews and observations were our empirical data collection methods. Data collection followed the following procedure: a research assistant provided explanations regarding the research topic, the problem being investigated, the study objectives, and how the confidentiality and anonymity would be guaranteed. Once these explanations were given, the participant was invited to sign the consent form, after which the interview was conducted. Our interview guide included demographic questions, as well as on their professional and family situation. The pivotal questions probed participants' knowledge of scientific research and their experience with being a patient partner in research studies. These questions attempted to elicit precisely how participants understood engagement and partnership in research. In this way, each participant was invited, for example, to share how they appreciated participating in our research, whether they would accept to be contacted again, and what might be a barrier to their engagement as a patient partner. To explore

more deeply why the patients could be or not be interested in research partnerships, we asked questions about daily occupations, living with diabetes, domestic reality, migration pathways, social integration, etc. The average duration of interviews was 1 hour.

During our interaction with the persons interviewed, we practiced what Weber and Lambelet (2006) call reflexive ethnography, which requires the interviewer to be continuously aware of the possibility of being intrusive on the participants, and to respect their way of being. For example, with participants from the Pakistani Muslim community in Laval (Montreal), we needed to respect some social codes when interacting with women. According to Islamic ethics, it is not appropriate for females to be interviewed alone by a male out of their home. Therefore, a female researcher from our team interviewed female participants in their homes. At their request, most of the male participants in this community were interviewed at a "Tim Horton's" (a fast food restaurant chain, specializing in coffee) near the Laval neighborhood Mosque. During the interview, in some cases, participants invited us to the Mosque when it was time for them to pray. After the prayer, we returned to the coffee shop to continue the interviews. The interviews were conducted in English with Pakistani participants as this was their usual language. However, many female participants were more fluent and comfortable speaking in Urdu, one of the official languages of Pakistan. Consequently, it was often necessary to ask someone from their community to translate Urdu to English. In Quebec City, interviews were conducted in French in the homes of participants, for most were French speaking from sub-Saharan Africa.

In addition to the interviews, observations reported in our journal were important to glean information such as patients' physical condition related to diabetes (e.g., weight, eyesight problems). The observations also provided insights to the non-verbal dimensions of the interviews, especially concerning the body language of participants (i.e., their gestures, grimaces) and to identify their emotions (e.g., embarrassment, hesitation). These non-verbal data are important to access to what remains implicit, for example cultural codes. The interviews were conducted within the limits of every participant's capacity and within the time frame planned, but flexible depending on the circumstances of each interview.

### **Analysis**

Our analysis highlights the opinions and perceptions of people new to Canada about their engagement in research partnerships, so we used content analysis (Elo & Kyngas, 2008; Thorne, 2016) to identify key themes. Our goal was to interpret, clarify, and explain what individuals shared while keeping in mind that concepts may be repeated for the importance and for the meaning that they hold for the speaker. The interviews were audio-recorded and transcribed verbatim in French and in English, depending on the language in which the interview was made. We did not transcribe the Urdu statements from audiorecordings, but only



**Table 1.** Characteristics of Study Participants.

Characteristic	N	Female	Male
Participants	31	18	13
Mean age	58	56	61
Country			
Pakistan	22	14	8
Democratic Republic of the Congo	1	0	1
Togo	2	2	0
Cameroon	2	1	1
Tunisia	1	1	0
Cuba	1	0	1
Martinique	1	0	1
Ivory Coast	1	0	1

the English translation. Each verbatim transcript was divided and classified into several sections according to our key themes. At all steps of the analysis, we grasped the meaning and significance transmitted in the interviews throughout the sorting and exploitation of the empirical material, in conjunction with our key topics (Blakoe et al., 2022). This procedure facilitated the identification of the points which were central to understanding opinions and perceptions related to barriers in engaging in research partnerships. However, some of these barriers are more salient and prevalent than others. In the social sciences, the salience of something is often defined in relationship to concepts such as remanence, invariance, optimization, relevance, meaning, prototype, and reification (Abric, 2003; Landragin, 2012). In our analysis, salience is related not only to the significance of a given problem or explanation in the interviews, its repetition, and recurrence in the statements, but also its difference, specificity, and distinctiveness. At all steps of the analysis, the written sources allowed us to note the convergence between our results and the available data, to show the limits of the existing literature, or to support our points. The non-verbal data (gestures, laugh, smile, hesitation, embarrassment, etc.) collected through observation allowed deep and interrelated understanding of quotes and to understand the context and some cultural codes.

## Findings

We conducted qualitative interviews with a total of 31 participants new to Canada living with type 2 diabetes in Montreal and Quebec City (age range 40–75 years; 58% females). The majority of participants (87%) had no prior research experience and four were DAC Network Patient Partners. 22 participants (71%) self-identified as Pakistani from Laval (64% females). The African-Canadian participants were from the Congo ( $n=1$ ), Togo ( $n=2$ ), Cameroon ( $n=2$ ), Tunisia ( $n=1$ ), and the Côte d'Ivoire ( $n=1$ ). One participant was from Martinique and another from Cuba.

Our findings indicate that the concept of “research” remain something nebulous for the majority of those interviewed. Nevertheless, most of them were willing to integrate research partnerships to share their experience only on an ad hoc basis. To be more precise, 19 participants (61%), mostly men, knew a little bit about scientific research, but only seven stated their readiness to collaborate as long-term partners in research without any conditions; the remainder either agreed to collaborate occasionally or were undecided and cautious. Reasons for their caution or rejection to engage in a research partnership were mostly due to the lack of time given their demanding schedules, stating: “*If I’m available,*” “*if I had time, I wouldn’t mind.*” Other challenges expressed by participants that may limit their engagement were as follows: health problems; uneasiness about their role in the research; a lack of knowledge concerning science; transportation difficulties; family obligations; a fear of being rejected; the fear surrounding confidentiality issues; the fear of being involved and manipulated; the fear of scientific experimentation; not wanting to talk about their diabetes all the time; and domestic problems. Globally, we identified six barriers that seem to be more salient and prevalent than others: *Lack of information; Competing priorities; Language barrier and privacy concerns; Preconceptions about being a patient partner; Research engagement as something demanding and binding; and The matter of religious and gender differences.*

### Lack of Information

Very few of the interviewed participants had ever heard of the possibility of becoming a DAC Patient Partner. For example, one participant was already retired and was invited to be a DAC Network patient partner through his professional re-qualification:

I was referred by a Tunisian friend. I am a researcher in breast cancer and by chance someone sent me to this woman who became my friend and I told her, please, do you know the light, the little door that could introduce me into the scientific world; to the professional medical world. So, she referred me to X. You understand? Things work by references here in Canada; this is the system: from mouth to ear [word of mouth]. (Montreal, April 2018)

### Competing Priorities and Heavy Schedule

We observed that most of the participants were involved in several activities related to their livelihood and have more than one job or on-call jobs. Consequently, they have demanding and changing schedules. They may also be single parents with dependent children, and when they are experiencing domestic problems (divorce, conflicts, etc.), it could be very difficult for them to be free for other commitments. Those who are married and have children need to devote time to their family as this patient explain:

I am a security guard waiting to find something better and I work at night. To have the chance to work during the day, you have to have seniority. So it's not easy for immigrants to start working during the day, because the list of those who have been there for years before you and who want to work during the day is so long. So the employer has no choice but to make you work at night. So we are forced to work in hours other than those we would have liked to work. Because when you have a family, you would like to spend time with the children to be able to take care of them during the day. (Quebec, April 2018)

Retired persons too, preferred occasional collaboration or were not interested, due to their commitments as volunteers in various places or their childcare responsibilities as relatives, parents, or grandparents. This is the case of this retired industrial engineer:

No it wouldn't interest me because I'm busy, not because I don't like it because I'm very busy, with the mosque, with the community really.

Q: Do you have responsibilities at the mosque?

A: Responsibility is that people wait for me to say if they want to have advice, so that's the responsibilities. They always expect me to be there, so that's a big responsibility. So that's really what I'm busy with, that's why, not because I'm against it. (Montreal, May 2018)

### Language Barrier and Privacy Concerns

Most of the participants were not fluent in either of Canada's official languages. For example, many participants from the Pakistani community, especially women, did not speak French at all. Some women who could speak English or French were only able to say basic things, but all were more comfortable speaking *Urdu*. In the same vein, most of the patients from French-speaking African countries neither spoke nor understood English. After explaining that they might be interested in participating in research projects, they however pointed out that language (e.g., English) could be a huge barrier to overcome. One patient from Pakistani community said: *"If it will be in another language it will be more difficult. In English there is no problem"* (Montreal, May 2018). In another interview, a daughter translated her mother's answer as follows (English/*Urdu*): *"she doesn't want to be in research. She will not feel comfortable to be translated every time!"* (Montreal, May 2018). Within the Pakistani community, the mediation of a translator (a member of the Pakistani community) certainly made things easier in recruiting participants and especially in collecting data, but their presence appeared to embarrass some female participants. For example, when we asked if their engagement in a research partnership would impact their family life and what their husbands would think. We also noticed that immigrants may be particularly heedful to the matter of anonymity and confidentiality. Some are very cautious about sharing their personal information, especially about their health, fearing to

be tagged as explained by this patient: *"People are afraid that for example the research could use their personal data; they will be known! So, they don't trust! I believe in research and in anonymity, because I am a health professional, I am a doctor, but not them, they have this phobia of being, how would I say, tagged"* (Montreal, May 2018).

Participants also let us know that talking about oneself and one's health is not something they always appreciate: *"My illness is not a public matter! So, why should I always talk about it? I don't want to be in something where I always speak about my diabetes. I do not mind advising other patients, telling them how to do this or how to do that, but I don't want to talk about my life to everyone [ . . . ]. I don't like that!"* (Quebec, February 2018). Additionally, we identified that diabetes' complications and domestic problems can lead to depression in such a way that the participant can lose motivation for everything including isolating his/herself, which was expressed by one participant who just wanted to stay home: *"I do not feel well, I have lost everything, my health, my wife, my children, I have no motivation for anything; I prefer to stay in my home. I don't want to engage please!"* (Montreal, May 2018).

### Preconceptions about being a Patient Partner

Some participants prejudice that research requires high academic qualifications: *"research is good, but as I told you, I've never been to school in my life,"* said one person with type 2 diabetes (Montreal, May 2018). Other participants indicated: *"maybe," "not sure," "I don't feel I am able!," "I'm not that person working in that kind of business so, I'm not really into it"* (Montreal, May 2018). These responses may indicate a hidden fear of not being qualified enough to participate in a research partnership. Indeed, it appears for many patients interviewed that research is something essentially academic, something complicated for less educated people as it requires specific skills that many cannot achieve. These perceptions greatly limit their interest in research partnerships. Participants also expressed that they are often contacted by telephone or e-mail from various companies and organizations to participate in surveys or for commercial purposes. Then they tend to associate research partnerships with such disruptive requests. Likewise, participants exhibited some a misunderstanding and negative perceptions about the role of being a patient partner since they tend to associate it with being experimented on rather than being a patient partner, highlighting that they may not understand the difference. For example, one participant asked: *"When you talk about research partnerships with us, is it about testing drugs or something else on us? I do not want to be a guinea pig for scientists, I've watched documentaries where scientists are experimenting many things with humans, but things didn't work out as planned. So, I don't want to be a guinea pig"* (Montreal, April 2018).

### **The Engagement in Research as Something Demanding and Binding**

Those who were reluctant to participate in research partnerships argued that they don't want to end up in something demanding and binding: "*Often things are presented in an attractive way, but once engaged, that's when you realize that it is more demanding than it seems. From then on, it becomes hard to go back!*" (Montreal, April 2018). So, it is clear that even though people new to Canada understand the benefits of a given research, they may resist to engage, especially if they perceive that in the long run, their collaboration may be demanding.

### **The Matter of Religious and Gender Differences**

It was among the Muslim female participants from the Pakistani community in Montreal, that questions relating to religious differences and gender were raised. Some asked for example to what extent their dress and head covering style (e.g., a hijab) may create embarrassment within the research environment and teams. They then recalled that in Quebec, the model of women being advocated by Islam raises sensitive debates. One participant explained that:

*You know that currently in Quebec, a debate on religious symbols is underway and is not about to end. However, we cannot deny what we are; as women, we are attached to our religious values, while respecting others. But it is not easy for people to accept it. Among the other women in these circles of science, we might appear too different, right?* (Montreal, April 2018)

### **Socio-Political Expectations**

An additional identified challenge was related to the non-bio-medical expectations of people new to Canada. Indeed, some patients interviewed were unaware of how valued their opinion is in creating a change, considering that funds often dictate research priorities. One participant noted, for example, that diabetes research particularly encourage new technologies and clinical treatments, while the priorities of people new to Canada tend to be social, psychological, political, and economic:

There is a tendency that I see more and more: the new technologies. For example, different kinds of applications for different types of problems. But I just wonder: Are we embarking on new technologies for commercialization [. . .]? Whom will this serve exactly? Does this really meet a need of patients and for which type of patients? Even if the research is not commercial, things sound like. And that's very dangerous! We do not immediately see all the impacts that new technologies could have for patients, but there will inevitably be economic and political consequences, while the research claims to be apolitical. (Montreal, April 2018)

He also wonder if the research partnerships will continue to escape patients' advocacy in relation to the social and political concerns:

There is a kind of allergy to things that would tend to be identified as a political option. For example, I had sent to X all the information about the immigration law, with the precision on the sections that could prevent someone from entering in Canada because of health reasons. So, operationally there is the possibility for an immigration officer to close the door to someone who has type 1 or 2 diabetes, because it's going to be a burden for public finances. It is not textually written like that, but there is this possibility. Many years ago, there has been denunciations in the courts and things have changed from 20 years ago, but the discrimination for health reasons is still possible. So, I sent this information to X, but will it have an impact? No, because that means that X has to lobby with the Canadian Immigration Department. I do not think it's going to happen. So that's what I mean by an allergy, a tendency not to touch things that might be political! (Montreal, April 2018)

The interview with this patient, as with others, clearly showed that the research partnerships may disappoint the socio-political expectations of people new to Canada and some patient may try to use their role of being a patient partner on a research project as a platform to discuss all kinds of claims.

## **Discussion**

We conducted an ethnographic study with people new to Canada living with type 2 diabetes, to highlight what, from their opinions, perceptions, and social contexts, may be barriers to their engagement in research partnerships. One of the most recurrent barriers expressed by participants is the lack of information and awareness about research partnerships. Indeed, out of the academic circles, it appears that very few people new to Canada living with diabetes have ever heard about research partnerships with patients. This shows that the communication around SPOR needs to be improved so that information about becoming involved in research partnerships is more widely available to people new to Canada. Indeed, if they are to become partners in research, they need to be offered the opportunity, otherwise they will continue to perceive the research as the prerogative of academics. Additionally, some interviewees did not distinguish between a research participant and a research partner, which shows the importance of explaining to patient partners what their role will be within a research partnership.

Language barriers are also important to consider toward improving communication about the research partnerships. Many studies have already documented this issue, pointing language barriers as limiting the involvement of people new to Canada in various sectors such as civic engagement, education, employment, and healthcare services (Bouchard & Desmeules, 2013; Bouchard et al., 2009). One potential solution might be the use of a translator. However, the issue of confidentiality and anonymity may be problematic, especially, as we noted among participants from the Pakistani community, where the translator and the participant belonged to the same community. Indeed, within their families and relatives, patients may experience some challenges that they



would prefer to keep private (Boulton, 1993; Vidal, 1995). Since the translator was considered part of the community, his presence may have been uncomfortable for the participant when talking about particular topics. We agree with Béliard and Eideliman (2008) that in qualitative research, we cannot assume that the issues of anonymity and confidentiality are assured by giving verbal or written consent. In particular, families, relatives, and communities can be considered as being sensitive to the research context, since they are “close acquaintance spaces” where they know each other, not only by “name” or “by sight,” but also through daily experiences (Béliard & Eideliman, 2008). Thus, research interviews could directly or indirectly lead people to talk about private issues, which could become “public information.” In the same vein, people need to feel comfortable to talk about their illness which normally is a private matter, considering that an interview could arouse emotions, shame, guilt, sadness, and painful memories (Smith-Morris & Manderson, 2010). Therefore, contrary to quantitative and statistical research, the anonymization procedures in qualitative research do not automatically solve the problem of anonymity and confidentiality (Béliard & Eideliman 2008, p. 136).

Another issue is that even though data collected from patients can be used for improving public health, this does not reassure people new to Canada who are asked to participate in research (Gopichandran et al., 2016) as many perceive research programs to have a hidden agenda or see them as insidious strategies to control people’s health and privacy (Carré & Vétois, 2016). For example, Dozon and Fassin (2001; Fassin, 2008) observed that HIV-positive patients in South Africa sometimes perceive the consent form as an insidious administrative listing. Robert et al. (2018) who conducted a study in Montreal also observed that filling out forms is not always perceived as harmless by people new to Canada and could actually be destabilizing for them, knowing that they are regularly called upon to complete government procedures related to their legal status.

In addition to dealing with the administrative challenges of their legal status, people new to Canada also need to work for their livelihood and many have multiple jobs with little free time to devote to their families. Additionally, studies have shown that people new to Canada have low incomes (Battaglini et al., 2014; Creatore et al., 2012; Ferzacca, 2012; Gravel & Battaglini, 2000; Manderson & Smith-Morris, 2010), working for arduous and unrewarding jobs (Martiniello, 1995), which is not conducive with a long-term research collaborations despite their goodwill. It might also be expected that patients who were retired would have more availability for long term participation in research, but this is not the case since many patients continue to be involved in social activities or take care of family dependents. Consequently, the requests for research partnerships may be perceived as too much in their already heavy schedule.

Although patients understand the merits of the SPOR’s objectives, patient engagement, as promoted by the CIHR and the DAC, requires an informed and motivated decision that many patients don’t want to make. To “engage” requires loyalty and may involve, even minimally, moral obligations, terms and conditions that need to be respected. Furthermore, to engage means to take sides for a cause that aligns with one’s values; it involves being consistent with oneself. However, the choices and decisions people make are not always based on good reasons and objective arguments, because they can be confronted with subjective preferences (Harang, 2006). So, when people realize they cannot assume the consequences of their engagement and when they do not understand all the implications of their decisions, they, could remain cautious. Moreover, they may be reluctant to participate if they do not understand what their role will be. Indeed, individuals evaluate things through their perceptions and representations (Abric, 2003; Guba & Lincoln, 1989). The consideration they give to a given thing can then be circumstantial and depend both on their context and background (C. B. Wilson & Clissett, 2011). Therefore, researchers should be as clear as possible to allow patients to make an informed decision about research participation (Kass, 2001) given the extent that differences in perceptions and interpretations by patients often create confusion and misunderstandings (O’Connor, 2015). Engagement to a cause does not automatically result from understanding the benefits thereof; people also act according to their values and beliefs. As such, any important personal decision is taken within the flow of a person’s life (Harang, 2006); it does not emanate from a punctual deliberation resting on the sudden reliance on the objective reasons to do something. One’s decision is “embedded” in the overall direction of his/her life. One’s choices thus reveals his/her values. This reality is relevant among the few people new to Canada who are already DAC Patient Partners, as collaborating with scientists was something they were used to through their professional careers. Indeed, they were either retired physicians or health professionals, social workers, or had qualifications in health and public policy studies. So, becoming a research partner was something aligned with their background.

Another aspect that could be unsettling for patients in research partnerships is the issue of gender and religious differences; the case of Muslim women. Indeed, our work showed that the barriers to the involvement of people new to Canada in research partnerships are grounded in their social condition rather than their will and skills to participate. Although women are more affected by diabetes (Creatore et al., 2012), they seem less interested in partnerships, particularly among the Pakistani community. Main reasons shared were language barriers, heavy schedules, and lack of educational skills. Cultural tradition and religion may also be a factor, as Muslim women try as much as possible not to have direct contact with men that they do not know. This



could make it challenging for these women to get involved in research partnerships. Contrary to what is common in Quebec, many Muslim women wear a hijab and when they are married, they may need their husband's permission before giving their consent to participate in research partnerships. This could be destabilizing for those who are not used to this way of life and raises the question whether healthcare professionals, nurses, and academics are prepared to deal with these situations which may contrast prevailing norms.

The challenge for research partnerships will then be to ensure that we provide optimal conditions for patients to have an effective platform for research deliberation and participation (Massé & Saint-Arnaud, 2003) by promoting equity, respect, and inclusiveness. Massé and Saint-Arnaud's (2003; Massé, 2012) calling for discussion of ethics is relevant within research partnerships to reach a consensus among all stakeholders. This includes creating spaces for open discussions with patients to break the status quo within research circles to ensure cultural sensitivity and inclusivity. The adoption of an ethics discussion with racialized patients within research partnerships could induce changes to protect patients such as to update the terms, conditions, and standards that guide the research partnership and to integrate for example terms on how to involve and engage with religious and gender minorities in a more culturally sensitive way.

However, the openness to discussion raises another risk, which is to see patient partners becoming activists, by defending causes or problems that a given research project may not necessarily be able to address. Yet, there is often an asymmetry between researchers and patients in decision making (Hamelin et al., 2018; Rolfe, 2000), and researchers can only act within the limits of what is allowed by the academic hierarchy and granting agencies, which often need to align their work according to predefined requirements (Hamelin et al., 2018). The researchers themselves have career goals which influence the way they conduct research. Thus, how can academics and granting agencies reconcile their goals with the needs of patients? Research partnerships with people new to Canada need to be done cautiously as to not create expectations that will never be met. Moreover, patients will not always say what researchers need to hear and some may take the research partnerships as a platform for advocacy and complaints. So, arguing its neutrality, can research partnerships with people new to Canada be able to ignore the social and political root causes of challenges that patients living with diabetes are facing?

### **Strengths and Implications for Health Practitioners**

This study fills an important gap in knowledge about involving a social group most affected by diabetes in research partnerships—people new to Canada living with type 2 diabetes. People new to Canada living with type 2 diabetes are less

represented in research partnerships, so their experience has not been adequately captured to address their specialized needs toward improving their care. There is an urgency for healthcare providers, especially nurses to become more culturally aware about racialized and ethnocultural minorities to better understand the problems they face in their daily lives, and to develop and implement clinical practices that are optimized to their needs. In Quebec where religious and gender debates are particularly sensitive, healthcare professionals would benefit from gaining knowledge about how best to interact with religious minorities such as Muslim patients living with diabetes. Fournier and Goiseau (2021) have already shown how important is the cultural awareness among nurses in Aboriginal context, but this awareness need to be extend to other minorities. Moreover, given the topicality of health issues related to global migration, our findings offer relevant avenues wherever one aim to help health professionals and nurses to develop cultural competences.

### **Limitations of the Study**

Our study also had some limitations. First, recruiting people new to Canada was a challenge, so we used a snowball sampling method, which allowed us to recruit patients living with type 2 diabetes mostly from the Pakistani community. Therefore, a large proportion of our sample was from this community, which limit the relevance of our findings to other culturally diverse people new to Canada. Second, our findings were consistent with the existing literature that language barriers limit any kind of engagement and participation in research (Bouchard & Desmeules, 2013; Bouchard et al., 2009). Many of our participants could only converse in Urdu. Even though we had a person directly translate from Urdu into English during the interviews, there is a possibility that this translation was biased. Lastly, our work also highlights the misunderstanding some patients may have about being a patient partner or being in a research partnership. This misunderstanding can be solved by informing and training patients. However, this may not be enough in situations where the misunderstanding is grounded in cultural, religious, or gender differences.

### **Conclusions**

Our work shows that people new to Canada living with type 2 diabetes are interested in sharing their experiences through research partnerships. Most of them prefer occasional collaboration rather than being long-term partners. The barriers to the engagement of people new to Canada are closely grounded in how “the research” is perceived, on their socio-economic situation and whether or not they are convinced that their view points are valued. Factors that limit their willingness to engage in research are language barriers, heavy schedules, and representations about skill requirements for participation. Another factor that contributes to

the reluctance of people new to Canada to participate in research is their perception that research is something that is demanding and binding, which could expose them to the potential of being tagged and enlisted by government institutions. Gender and religious differences within Canada's multicultural society are other matters that may raise ethical issues. It is clear that focusing only on biomedical objectives within diabetes research partnerships is not enough. We need to focus on social and ethnocultural criteria to enable the development of strategies that can improve the involvement of diverse population groups affected by diabetes in research partnerships, to better understand their way of life, to better interact with them within partnerships, to prevent some misunderstandings and ethical problems, and to better address their needs. The challenge is great and we acknowledge that it would not be possible for research partnerships to adapt to every ethnic group. However, the SPOR needs to increase opportunities to involve more people new to Canada so that it truly reflects the equity, diversity, and inclusion of patient partners it advocates. As our findings show, patients will not automatically engage in a given research partnership just because they understand its benefits and importance. Research goals also need to align with their values and ways of life. Science may be neutral, but individuals are not.

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### ORCID iD

Séraphin Balla  <https://orcid.org/0000-0002-4211-4116>

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researchers' experience. *International Journal of Social Research Methodology*, 21(1), 7–24. <https://doi.org/10.1080/13645579.2017.1296714>

### Author Biographies

**Séraphin Balla** is a Lecturer at the University of Yaounde I, Faculty of Arts, Letters and Human Sciences, Department of Anthropology, Yaounde, Cameroon. He is also a lecturer in the Department of Anthropology at Laval University.

**Maman Joyce Dogba** is a Professor at the Laval University, Department of Family and Emergency Medicine, Faculty of Medicine; and a researcher at VITAM—Center for Sustainable Health Research; Integrated University Health and Social Services Center of the Capitale-Nationale (CIUSSS-CN). She is being supported by the junior salary award of the FRQ-S.

**Monika Kastner** is Research Chair, Knowledge Translation and Implementation at North York General Hospital and Associate Professor, Institute of Health Policy Management and Evaluation, Dalla Lana School of Public Health at the University of Toronto.