

ORIGINAL RESEARCH ARTICLE



# Ethnographic study of the barriers and facilitators to implementing human papillomavirus (HPV) self-sampling as a primary screening strategy for cervical cancer among Inuit women of Nunavik, Northern Quebec

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## ABSTRACT

The rate of cervical cancer among Canadian Inuit women is higher than the national average. To date, early detection remains the best strategy for reducing the incidence of cervical cancer and its consequences. Thus, the aim of this study was to explore the barriers and facilitators in implementing human papillomavirus (HPV) self-sampling as a primary screening strategy for cervical cancer among Inuit women of Nunavik in Northern Quebec. A focused ethnographic approach was adopted. Inuit women of Nunavik participated in individual or group interviews during which a semi-structured interview guide was used to determine their perceptions of the barriers and facilitators to implementing HPV self-sampling as a primary screening strategy for cervical cancer. The data were analysed based on Paillé's grounded theory of qualitative analysis. Twenty-eight Inuit women participated in this study. Analysis revealed five subcategories of facilitators and four barriers. Inuit women may embrace the self-sampling method. Importantly, in order to be effective, these strategies must be culturally sensitive and adapted to women's preferences so as to increase sustainability. The results of this study provide the means for integrating the perspectives of Inuit women in implementing HPV self-sampling as a primary screening strategy for cervical cancer in Nunavik. Consideration of these facilitators and barriers might maximise the chance of success and optimise the screening participation rate.

## ARTICLE HISTORY

Received 8 September 2021  
Revised 23 December 2021  
Accepted 18 January 2022

## KEYWORDS

Human papillomavirus (HPV); self-sampling; cervical cancer screening; Inuit women; ethnography

## Introduction

Nunavik is a region located above the 55<sup>th</sup> parallel in the northernmost part of the Canadian province of Quebec. More than 13,000 Inuit [1] living in 14 communities located along the coast share this vast territory of 507,000 km<sup>2</sup> [2]. In Nunavik, cervical cancer screening is performed opportunistically with the Papanicolaou (Pap smear), whereby there is no systematic recall system in place to encourage women to adhere to time appropriate screening. A previous study revealed that 24% of Inuit women in Nunavik did not undergo a Pap test within the recommended time frame [3]. The reasons for this vary, but may include structural barriers to accessing screening and the intercultural context in which healthcare services are embedded [4]. As a result of such barriers, the prevalence of cervical cancer is 2 to 3 times higher among Inuit women than the Canadian population more generally [5].

HPV is the necessary cause of cervical cancer [6,7], and the prevalence of infection with known oncogenic HPV types affects 20.4% of Inuit women in Nunavik [8].

Moreover, HPV screening performed by a health care provider or via self sampling has been shown to be more sensitive than the Pap test in detecting cervical cancer [9–11]. More particularly, HPV self-sampling has the potential to overcome certain barriers associated with the Pap test and reach more underscreened women [12,13].

To date, early detection through screening remains the best strategy for reducing the incidence of cervical cancer. Thus, the purpose of this study was to explore the facilitators and barriers to the implementation of HPV self-sampling as a primary screening strategy for cervical cancer among Inuit women in Nunavik.

## Theoretical framework

This research project was guided by Purnell's model for cultural competence [14,15]. This model helps to provide culturally sensitive and competent care to improve outcomes for clients. As described by Purnell [14], it is a holistic and flexible model that can also be used to

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guide data collection and research. More precisely, the project relied on the following four explicit assumptions of the Purnell model [14] for its development:

**If clients are coparticipants in care and have a choice in health-related goals, plans, and interventions, health outcomes will be improved.** This assumption justifies the aim of this research which is to identify the barriers and facilitators to implementing HPV self-sampling as a primary screening strategy for cervical cancer among Inuit women of Nunavik. Thus, by prior consulting the concerned individuals, it becomes easier and realistic to obtain essential data for an eventual successful implementation which, ultimately, would help reduce the burden of cervical cancer in this population.

**Culture has a powerful influence on one's interpretation of and responses to health care.** This assumption recalls the importance of taking into account cultural differences in the development of health care, because it has an inevitable influence on the response and therefore the success. Hence, it was essential that this project be organised in such a way as to consult Inuit women to obtain data consistent with their cultural particularities.

**Prejudices and biases can be minimised with cultural understanding.** This is why it was important that the members of the research team had already been exposed to the Inuit culture. In addition to allowing cultural sensitivity throughout the course of the research, this helps ensure a more accurate interpretation of the data while minimising possible biases.

**Differences in race and culture necessitate different interventions.** It is the underlying reason why this research project took place. It was not possible to simply implement HPV self-sampling in Nunavik based on what is done in other settings without first consulting Inuit women. If we aim to increase the chances of success of a possible implementation, considering that the needs of Inuit women may differ from the general population is the starting point.

## Methods

A focused ethnographic approach was used to highlight the specific context of the Nunavik Inuit communities [16–18]. Focused ethnography differs from traditional ethnography in that it focuses on a specific situation (the facilitators and barriers to HPV self-sampling) in a specific context (Inuit culture) and within a specific group (Inuit women over the age of 21), rather than on a population or organisation per se [16,18,19]. It is characterised by an intensive data collection in a short period of time[18]. Focused

ethnography also provides an emic perspective[16], which aligns with the purpose of this research of identifying the potential facilitators and barriers to HPV self-sampling as perceived by Inuit women themselves. As the aim of this study was very specific, the use of focused ethnography was more appropriate than traditional ethnography that relies on long-term data collection and immersive participation.

According to Fetterman [20], the ethnographer's most important data collection technique is the interview, either individual or in group. In order to answer the research question, we focused on this technique as the most adequate to collect the necessary data.

The study was conducted from October to November 2018. Participants were recruited from two Nunavik communities as well as in a metropolitan short-term lodging facility exclusive to Nunavik Inuit who must travel to urban Quebec for medical purposes. The choice of communities was based on previous collaboration for other research projects, which led to the development of a trusting relationship between the communities and researchers. Snowball sampling was conducted with the collaboration of local Inuit women. To facilitate recruitment, radio announcements in English and Inuktitut were aired in the two target communities. A short message explaining the presence of the researchers and the research's purpose was aired. Women were invited to participate in interviews to answer questions related to cervical cancer screening strategies and gather their opinions on barriers and facilitators for HPV self-sampling. This same message was aired by the intercom of the urban accommodation. However, the success of recruitment was mainly related to the fact that one or more key women of the communities joined the researchers in order to actively recruit volunteer participants. As per Inuit women's suggestion the research project was called "study about cervical cancer screening" and was used as such for recruitment. In order to be eligible, participants had to be Inuit women present in one of the two communities or staying at the lodging facility at the time of data collection. They had to be between 21 and 65 years old, which is the current recommended age for cervical cancer screening[21]. However, recruitment was organised in collaboration with local Inuit women and they included women over the age of 65. According to traditional Inuit culture, people are expected to hold elders in high regard[22]. Since respecting the views of elders is an integral part of Inuit culture, we included those women. It is also mentioned in the Ethical Principles for the Conduct of Research in the North [23] that "Mutual respect is important for successful partnerships. In the case of northern research, there

should be “respect for the language, traditions, and standards of the community [...]”[23]. In accordance with the ethical principles specific to northern communities the project was adapted as such.

The entire project (“Illiap Paanganik Qaujisarniq” (“Cervical Screening” in Inuktitut)) in which this study takes part, was reviewed at every step by an Advisory Committee composed of members from the Nunavik Regional Board of Health and Social Services (NRBHSS), the Ungava Tulattavik Health Center (UTHC), Saturviit Inuit Women’s Association, as well as rotating individuals from the communities where the research was conducted. The team followed the AC’s recommendations as per where and how to reach women and discuss cervical cancer screening. Upon arrival in both communities, women and staff on-site conducted most communications and recruitment. The success and relevance of this project lies in the recommendations, engagement and collaboration of these individuals and communities, without which this project could not have been made possible.

Verbal consent was obtained from each of the participants before the discussions began and was chosen to respect the Inuit oral tradition and the variable levels of literacy of the participants. Snacks and refreshments were provided, but no monetary compensation was given.

The sample size was justified by data saturation, the guiding principle of qualitative sampling[24]. Individual and group interviews were conducted in facilities generously made available to the researchers (Family House, city hall, community organisations, etc.). The average length of each interview was 90 minutes and adjusted to the availability of the participants and the level of exchange. The interview ended when participants felt they had answered the questions and had nothing else to add. The number of individuals in each group ranged from two to six participants. The size of each group was self-defining as it relied on participants who showed up. Individual interviews were personal preferences expressed by the participant, and such a choice was respected. The field presence required to collect the data was 10 days in Nunavik and 2 days at the urban lodging facility. The interviews were conducted using a semi-structured interview guide based on Paillé’s method[25]. The purpose of this guide is to structure the interview to maintain sensitivity to the reality of each participant. It allows flexibility within discussions while adhering to the initial research objectives. The Paillé’s method takes place in six steps [25]:

- (1) The elaboration of the first draft which represents the brainstorming. It is at this stage that

the elements to be questioned such as: the perception of the technique, the educational needs, the level of knowledge on the problem and the vision of the organisation of the screening were written down.

- (2) The thematic grouping of questions related to the research topic.
- (3) The internal structuring of the themes according to a logical and strategic order.
- (4) Deepening of the themes.
- (5) The addition of probes which makes it possible to identify the researcher’s expectations regarding the responses of the participants
- (6) Finalisation of the guide. (see Appendix)

Once the final version was ready, face validation of the interview guide was obtained from colleagues not involved in the study and subsequently adjusted according to their comments.

As the interviews and data collection were carried out, the researchers made sure to validate emerging concepts with the participants in order to ensure accuracy and avoid misinterpretation during analysis. The use of individual and group interviews allows for triangulation of the data-collection methods. Moreover, the wide range of participants helped maximise data credibility by allowing for a variety of perspectives[26]. Voluntary participation without incentives may also be viewed as an element that increases credibility[26].

Two female investigators (RG and ET), who have previously lived and worked in Nunavik, conducted the individual and group interviews. To ensure that participants had a sufficient understanding of the research topic, each interview began with a short presentation on HPV, cervical cancer and the relationship between the two. Each then ended with a demonstration of the self-sampling technique with the use of visual aids. The interviews were conducted in English. When necessary, translation was provided for women who spoke only Inuktitut by an accompanying person who spoke both English and Inuktitut.

The individual and group interviews were not recorded in order to foster a trusting environment, as well as to anticipate discomfort with the right to refuse recording and to avoid self-censorship of responses. The primary interviewer had the role of animator and was leading the discussion when the second interviewer had the role of observer. The second interviewer was responsible of writing down participants’ responses. When detailed notes were not possible due to the rapid flow of conversation, key words were noted and detailed directly following the discussion to avoid missing any meaningful content from the exchanges.

**Table 1.** Age of participants.

Age (Years)	Number (n = 28)
21–30	7
31–40	6
41–50	3
51–60	5
61–70	4
71–80	3

In terms of dependability, a logbook and memos [27,28] were maintained throughout data collection. A debriefing took place after each individual and group interview. The logbook and handwritten verbatim records were completed, clarified, and enhanced, as necessary. The data were verified by the other members of the research team. Empirical data saturation was reached; the researchers observed a redundancy of content at the end of the interviews.

The data collected from the interviews and the logbook were co-analysed by the two field researchers and coded with QRS NVivo 12 software. They were then reviewed by the other team members. If there were disagreements on the coding, team discussion was used to come to a unanimous agreement. Verbatim comments were carefully selected in presenting the results[29].

The analysis was based on Paillé's grounded theory method of qualitative analysis[25]. The first three steps (1) coding, (2) categorisation, and 3) relating were used to produce the results presented below[30].

## Results

A total of 28 women between the ages of 26 and 78 (Table 1) participated in one of three individual interviews or seven group interviews.

### Facilitators

The facilitator category includes six subcategories: (1) acceptability of the self-sampling method, (2) information diffusion strategies, (3) nurse involvement, (4) being able to choose the sampling method, (5) available information about cervical cancer prevention, and (6) feeling concerned about cervical cancer prevention. (Table 2)

#### Acceptability of the self-sampling method

Some participants indicated that they would prefer self-sampling as stated by this participant: "For me, I would like to use that instead of the Pap test" (P26). The advantages of not having to get undressed in front of healthcare professionals, the rapidity of the technique,

**Table 2.** Summary of barriers and facilitators.

Facilitators
1.1 Acceptability of the self-sampling method
1.2 Nurse involvement
1.3 Being able to choose the sampling method
1.4 Available information about cervical cancer prevention
1.5 Information diffusion strategies
1.6 Feeling concerned about cervical cancer prevention
Barriers
2.1 Not feeling concerned about cervical cancer prevention
2.2 Lack of confidence in the ability to perform self-sampling
2.3 Cross-cultural context of health-care delivery
2.4 Questioning the effectiveness of self-sampling

and not having to undergo speculum insertion were all arguments in favour of using the self-sampling method, as illustrated by the following quotes:

We would not have to open our legs in front of professionals (P7).

I would be emotionally comfortable with the technique yes (P11).

I think more would come for self-sampling. I know some of my friends feel intimidated by Pap-test. They think it is invasive personally and physically. One of my friends told me "I don't want to go because I don't want a plastic thing in my vagina." So yeah, I think having the choice to go by themselves, they would definitively go (P14).

This one would be more flexible. It takes less time (P20).

### Nurse involvement

Routine Pap tests in Nunavik are mainly performed by nurses. The majority of participants identified the involvement of nurses as a facilitator to encourage adherence to HPV self-sampling. When asked "*What would be the most important thing to consider for this project to work?*" one participant responded: "Having nurses involved" (P1). Many participants who would be willing to perform self-sampling wanted the nurse to explain the technique before proceeding. They recommended a short presentation of the technique similar to what the researchers provided prior to beginning the interviews, as suggested by this participant: "People would be more interested with explanation by the nurse like you did" (P28). In addition, the presence of the professional nearby provides support should the need arise. This is one of the reasons why many participants preferred self-sampling in a clinic over self-sampling at home.

#### Being able to choose the sampling method

The interviews show that offering the option of self-sampling or provider sampling (either Pap smear or

HPV sampling) was essential in order to reach the greatest number of women, as brought out in one logbook excerpt:

Some participants consider it obvious that they would be comfortable using it [the self-sampling technique], but still acknowledge that some women won't be comfortable with it and would prefer to have a nurse doing it. So far, the possibility to have a choice seems to be essential. We exchange on the fact that there is two different kind of person: "the shy and the not shy". Some would prefer a nurse, some would prefer to do it by themselves. They say that having the possibility to choose would be a good thing, we would reach more people this way (P7, P8, and P11).

A participant in another group shared a similar comment:

Some ladies are shy, and some are not. The ones that are not shy could go with nurses and those that are shy could go with self-sampling. Sometimes women get scared and they don't go. It is a good thing this technique (P13).

The researchers found that older women that participated tended to prefer to have screening performed by a nurse.

### ***Information about cervical cancer prevention***

The participants identified the importance of education as a facilitator for the eventual success of implementing HPV self-sampling for cervical cancer. In Inuit culture, there is a taboo around sexual health, as mentioned by this participant: "There would be less taboos if we talked about it. Cervical cancer has to do with your overall health. It is part of your body and your body is part of your health" (P14). She added that "it comes back to education" (P14). For this reason, the participants mentioned that it is essential to inform the Inuit population about cervical cancer and the strategies for preventing it in order to reduce the myths and taboos surrounding the subject.

### ***Information diffusion strategies***

The women commented on the information diffusion strategies that can be used. Many suggested that there should be a step-by-step pamphlet to present the self-sampling technique. Some of the women, however, mentioned that they would prefer to have a healthcare professional explain the technique to them individually, as this participant explained: "There is two kind of person, by sheet and by nurse" (P7).

Some participants mentioned that they do not speak English well and prefer their native language, Inuktitut.

"It should be available not only in English but also in Inuktitut. Not everybody understands English well" (P2). Another participant added that "people don't read Inuktitut well and videos have more impact" (P5). It is therefore important that the educational material be visual as highlighted by this participant: "Inuit are very visual" (P14).

### ***Feeling concerned about cervical cancer prevention***

Over the course of the interviews, we observed that some participants felt particularly concerned about cervical cancer and prevention strategies: "Nobody can say they are not concerned, even men. It could be your mom" (P14). Moreover, the participant quoted above added that if women are well informed about cervical cancer that "they will want to participate; they will feel concerned" (P14). In fact, the interviewed women who felt concerned were in favour of implementing self-sampling, knowing that it could increase screening participation for cervical cancer.

### ***Barriers***

This section presents the four subcategories that emerged from the analysis of barriers: (1) not feeling concerned about cervical cancer prevention, (2) lack of confidence in the ability to perform self-sampling, (3) the cross-cultural context of healthcare delivery, and (4) questioning the effectiveness of self-sampling. (Table 2)

### ***Not feeling concerned by cervical cancer prevention***

During the interviews, it emerged that the women were unaware that HPV was a sexually transmitted infection (STIs). Once the subject was clarified, it appeared that the women who did not feel concerned by the screening strategies, were those who did not feel at risk of contracting STIs as illustrated in many comments: "I don't go anymore (to get screened) because I am staying away from boys ... I am not active anymore, I am getting old!" (P1) to justify no longer participating in screening. The comments of participants P23 and P24 (translated by another participant) also attest to this: "They don't want to have sex anymore". They don't want to be touched anymore. They say they are too old for that." Being in a relationship with the same partner for several years was another reason given by participants for not feeling concerned about screening.

The delay of several years needed for cervical cancer to develop following the initial HPV infection, as well as the asymptomatic nature of HPV were two aspects that



seemed to contribute to not feel concerned. A participant added that “Inuit need to see to believe” (P8).

### ***Lack of confidence in the ability to perform self-sampling***

Most of the women who wanted a health-care professional to collect the sample stated that they had doubt in their own ability to perform the technique. One participant stated: “I don’t trust myself, I want a nurse to do it” (P5), while another confided: “I am scared to mess it up” (P18). As soon as she was told about a study demonstrating that Inuit women are able to perform self-sampling just as well as a healthcare professional, P18 said: “If I was told properly I would [use self-sampling]. Like step by step”.

It would seem that a lack of knowledge of female anatomy might be a reason why some women are not comfortable with the idea of vaginal self-sampling, as this participant illustrated: “Because they don’t know where their vagina is” (P5). She shared a situation in which her friend mistook her urethra for her vagina when she performed a similar technique for an STD test. Participants in this group agreed that many women do not know how to identify the different parts of their genitalia.

### ***Cross-cultural context of health-care delivery***

In Nunavik, the majority of health-care workers are non-Inuit and speak English as a second language, which raises issues of free and informed consent, as expressed by this participant:

I think more women would participate if they were well informed. A lot of women felt like somebody was trying to force them. They need to know. We have to consider informed consent ... It needs to be available in Inuktitut or else it is not an informed consent (P14).

In addition to language, the healthcare system is poorly adapted to the cultural context, as illustrated by this example from a participant:

Imagine, I have experienced sexual violence. I am an Inuk. I am intimidated. This is not my language [referring to the fact that medical services are mostly available in English or French]. It is a stranger and I have to go for screening. There is a cultural barrier, language barrier. Also, nonverbal communication matters. Some things are acceptable in some culture and, in other, it is not acceptable. Take the example of visual contact. In my (Inuit) culture, it is not respectful to hold visual contact when we speak to someone but, in some culture, you know ... [We discussed the fact that, in our culture (Caucasian Canadian), holding visual contact is

a sign of respect and meaning that one is attentive to the words of the other]. (P14)

Inclusive and culturally adapted service delivery would remove many barriers, as this participant pointed out:

This will break the barriers if we know those things. We are minority, preventing those barriers to have the care we deserve, no matter who you are, as long as everybody has the same access to care ... Wording is very important. There is a high rate of drop out in school, keeping in the back of our mind the educational situation. It needs to be easily understood by everybody. (P14)

### ***Questioning the effectiveness of self-sampling***

Several participants questioned the effectiveness of the test in comparison to the Pap test, as demonstrated by this participant’s question: “My concern is, is it effective? I had Pap test all my life” (P20). Participants were pleased to know that, for primary screening, this technique is more sensitive than the current Pap test[9]. Participants also questioned the quality of self-sampled specimens versus those collected by a healthcare professional. The translated comments of this participant support the aforementioned doubt: “She (P28) asks in Inuktitut if the efficacy of this test is the same than if it’s made by a healthcare provider”. The researchers informed the participants that a study, which took place in Nunavik as well, showed that the self-samples collected by the women were just as good at detecting HPV as those taken immediately afterwards by a healthcare professional using a speculum[31]. They were therefore reassured. Other questions such as “Can we do it if we are pregnant?” (P27) and “Would it be every year like pap test?” (P5) were addressed.

## **Discussion**

This study is one of the first to explore the facilitators and barriers to HPV self-sampling in the female Inuit population of Nunavik, the findings of which are consistent with what has been previously reported for Indigenous populations[32]. This study thus serves as a starting point for implementing HPV self-sampling in the Nunavik context. Individual and group interviews with the Inuit women who participated revealed that the self-sampling method is very well accepted. The possibility to choose between HPV self-sampling and provider-collected sampling was found to be important. These results are consistent with a study that also took place in Nunavik that showed that HPV self-sampling was preferred by 56% of the women over provider sampling using a speculum[33]. The main reason for this provided by women was the belief that

a healthcare provider would take a better quality sample for detecting HPV. The doubt around the effectiveness of the self-sampling method also arose as a point of concern in this study. Fortunately, another study conducted with Inuit women in Nunavik showed that the HPV yield of samples taken by women were as good as those taken by health-care professionals[31]. In our study, the fact that participants were reassured when provided with this information and about their ability to perform self-sampling suggests that, with effective information diffusion strategies, Inuit women may embrace the self-sampling method. Importantly, in order to be effective, these strategies must be culturally sensitive [34,35] and adapted to women's preferences so as to increase the chances of success. Above all, many participants emphasised that what works for some might not necessarily work for others, and that in order to reach the most women, this notion must be taken into account.

A previous study among Inuit women showed that awareness of cervical cancer was low[36]. These findings are consistent with those of our study, as many participants emphasised the need for more information about cervical cancer. Therefore, Inuit women would benefit from having culturally adapted information available and relevant dissemination strategies in order to understand the importance of screening and to ultimately adhere to it. Others studies showed that improving women's knowledge about HPV and personal risks could increase the uptake rates. [37]

The present study showed that the women who felt more concerned by cervical cancer prevention during the interviews were in favour of screening. At the opposite, a study found that a low perceived risk is a barrier to cervical cancer screening[38]. This is coherent with our research showing that women who do not feel concerned about cervical cancer screening do not plan to get screened. Thus, to implement HPV self-sampling as a primary cervical cancer screening strategy, collaboration of women who feel concerned by cervical cancer prevention could be a strategy for reaching out to women who do not.

The cultural context in which care is provided cannot be ignored and should serve as a pillar in all stages of the eventual implementation of HPV self-sampling as a primary screening strategy for cervical cancer. Previous studies have shown that the attitudes of healthcare providers and their ability to build trust with Indigenous women influence the women's willingness to be screened for cervical cancer [39,40]. It is therefore essential that health-care professionals learn and adapt their interventions to the cultural context of the Inuit population[4].

Results of this research will be sent to key members of the community in order to share the results with other women.

## Limitations and strengths of the study

This study circumvents more colonial approaches in which a particular way of doing things is imposed on a particular population. Nevertheless, one limitation is that the data was analysed by non-Inuit researchers and the final analysis was not validated by the participants. In addition, the transferability of the findings should take into consideration that the particularities of the Inuit communities of Nunavik might not represent the general population or other indigenous communities.

Finally, voluntary and non-random participation affects the results. Women who participated in the research may over-represent those in favour of cervical cancer prevention strategies and could explain their motivation to participate in the interviews. Therefore, barriers could be under-represented.

One of the postulates of Purnell's model for cultural competence is that prejudices and biases can be minimised through cultural understanding[14]. Thus, the knowledge of the environment and its specific culture by the team members ensured a good cultural understanding as well as a cultural sensitivity. Moreover, the ethnographic approach allowed flexibility and adaptability, which are essential for community-based research to be effective in improving health. Finally, a strong aspect of this research is that we were able to recruit enough participants to be able to reach data saturation.

## Conclusion

The results of this study are based on the perspectives of Inuit women regarding the implementation of HPV self-sampling as a primary screening strategy for cervical cancer in Nunavik. Consideration of these facilitators and barriers might maximise the chance of success of implementation, optimise screening participation and decrease the burden of cervical cancer in a population disproportionately affected by cervical cancer.

## Acknowledgments

We would like to thank the participating community members, as well as the urban center staff and patients for their generous collaboration and genuine interest in this project. Special thank you to Christina Santella for reviewing the manuscript for consistency.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

This work received funding from the Ministère de l'Éducation et de l'Enseignement Supérieur du Québec (MÉES), and from the Canadian Institutes of Health Research (CIHR).

## Compliance with ethical standards

The project was approved by the Research Ethics Board at the Université du Québec à Trois-Rivières (CER-18-248-07.27) and McGill University Institutional research board (A06-E46-18B).

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