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## **Cover Page Footnote**

We would like to thank all participants for their time and for sharing their experiences. We would also like to thank Cheryl Proceviat-Ganes for proof reading this manuscript.

## Patient participation in medical consultations: the experience of patients from various ethnolinguistic backgrounds

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### Abstract

Patient participation in health care is a priority. Yet, patients' perspective with regards to their experiences of participation is not well understood. Moreover, few studies have attempted to explore the perspective of ethnolinguistic minority patients. The objectives of this study, to explore 1) patients' experiences of participation in medical consultations with physicians, and 2) potential variations in these experiences based on participants' ethnolinguistic status. Using a qualitative design, 60 participants, from various ethnolinguistic background, took part in individual semi-structured interviews. A content analysis was performed to identify emerging themes. The results, five themes emerged in response to the first objective and are organized in two key dimensions: a) participation in terms of information exchange (e.g. asking questions, providing information), and b) participation in terms of assertive behaviours (e.g. setting the agenda, expressing one's viewpoint, making a request). Across these themes, two levels of participation emerged: proactive participation (i.e. patient initiated) and responsive participation (i.e. physician initiated). Proactive participation was discussed more often. Patients also discussed experiences of non-participation, although these were less common. In response to the second objective, patients who faced a language barrier, regardless of their ethnic background, discussed less participative experiences. In general, participants spoke positively of experiences in which they participated, thus suggesting that patient participation is valued by patients. Patients seemed to have a broad view of patient participation, thus suggesting that the concept of patient participation should be extended beyond participation in decision-making. Language fluency seems key to ensure patient participation.

### Keywords

Patient experience, patient participation, physician-patient communication, qualitative methods, language barriers, ethnolinguistic minority

### Introduction

Patient participation in healthcare consultations has been advocated by researchers, healthcare providers and policy makers, and has become a priority in healthcare delivery.<sup>1-3</sup> Previous studies revealed there are benefits in promoting patient participation in healthcare.<sup>4,5</sup> For instance, patients who participate more have a better understanding of their treatment and better adherence,<sup>5-7</sup> and patient participation has been linked to better health outcomes.<sup>8-10</sup>

Patient participation has been used interchangeably with other terms, such as patient empowerment, activation, and involvement. Efforts to distinguish these concepts have been made,<sup>3,11,12</sup> and the definitions of patient participation vary from specific definitions (e.g. participating in decision-making) to broader definitions (e.g. participating in maintaining one's health).<sup>13</sup> Thompson<sup>3</sup> suggests a middle-range definition of patient participation as "*patients taking an active part in their consultations with professionals*".<sup>3, p. 1299</sup> This definition emphasizes the relational aspect of

patient participation and highlights the dynamic process inherent to patient participation, without restricting it to participation in decision-making.<sup>1</sup>

To better operationalize patient participation in medical consultations, researchers have suggested various indicators, components, and levels of patient participation. For instance, some researchers identified four key observable indicators of patient participation: information-seeking utterances, information-provision utterances, assertive utterances, and expressions of concern.<sup>14,15</sup> Other researchers suggested a five component model of patient participation (e.g. participation in setting the agenda, decision-making, etc.).<sup>16</sup> Across one of these five components, the authors distinguished between initiative participation and responsive participation, depending on whether the participation was initiated by patients or by physicians.<sup>16</sup> Overall, past research suggest that patient participation may take various forms and levels.

Much of the research on patient participation is conducted on consultation transcripts (e.g. conversational analysis),<sup>1</sup> uses observational methods to explore observable attributes of patient participation,<sup>15</sup> or uses quantitative measures and questionnaires (e.g. Patient Activation Measure).<sup>17,18</sup> Moreover, many previous studies focused specifically on participation in decision-making.<sup>12,19,20</sup> Although this body of research has been very informative, it offers a limited understanding of how patients perceive and experience their participation in health care. Gaining a better understanding of patients' experiences has become a central concern in healthcare research and policy<sup>21</sup> and there is a call for more qualitative research investigating patient participation from the perspective of patients.<sup>1,3,22</sup>

Furthermore, in the context of high migration movements and health disparities affecting ethnolinguistic minorities, it seems crucial to pay close attention to the experiences of patients across diverse ethnolinguistic groups.<sup>1,14</sup> Indeed, research on physician-patient communication has identified important barriers (e.g. discrimination, differences in values, language barriers, etc.) that act as obstacles to physician-patient communication in intercultural contexts.<sup>22,23</sup> Since patient participation is a key component of healthcare communication, it is possible that these barriers also affect ethnolinguistic minority patients' experiences of participation.

To date, few studies have investigated patient participation across a diverse group of patients. These few studies were conducted in the United-States and in the Netherlands and they revealed that ethnolinguistic minority patients are less likely to participate in medical consultations.<sup>18,24,25</sup> Language seems to play a key role: Ethnic minorities who speak the language of the host society fluently participate more than their counterparts who face linguistic barriers.<sup>18,25</sup> These studies favoured quantitative methods, which limit our understanding of the perspective of ethnic minority patients.

Little is known about the experience and the perspective of ethnolinguistic minorities with regards to their participation in medical consultations. Considering the benefits associated with patient participation, a broader understanding of patient participation, from the patients' perspective is needed, while paying close attention to variations based on patients' ethnolinguistic background.<sup>1,26</sup>

## Research Objectives

Overall, this research project sought to address two objectives: a) Explore patients' subjective experiences of participation in medical consultations with physicians, and b) explore possible variations in patients' reported experiences as a function of their place of origin and linguistic minority status.

## Methods

### Study Context

This study took place in Québec-City, capital of the province of Québec (Canada). Whereas Canada has two official languages (French and English), the province of Québec only has French as its official language. French-speakers form the majority group in Québec, although they represent a minority within the Canadian context.

The population of this province is fairly homogenous in terms of its linguistic and ethnic composition. In 2016, 77% of residents reported French as their first language<sup>27</sup> and only 13.7% of residents self-identified as a visible minority.<sup>28</sup> Québec-City is even more homogenous with 92.5% of residents reporting French as their first language, only 1.4% reporting English as their first language, and 5% reporting a first language other than French or English.<sup>29</sup> In 2016, only 6.4% of residents in Québec-City self-identified as a visible minority.<sup>29</sup>

Sociohistorical tensions have long defined the relationship between the English-speaking and French-speaking populations of the province of Québec. Up until the Quiet Revolution in the 1960s, the English-speaking minority benefitted from a higher social status as they controlled much of the economy in Québec.<sup>30</sup> These sociohistorical inequities may still foster a sense of inequity and insecurity for the Francophones and may continue to lead to tensions between these two groups. A study on discrimination in Québec revealed that being born outside of Québec and self-identifying as Anglophone were significantly linked to experiencing increased perceived discrimination.<sup>31</sup>

In turn, this larger sociohistorical context in which the medical system operates may influence physician-patient relationships, and current societal attitudes may transpire during medical consultations.<sup>32,33</sup>

### Study Design

A qualitative design based on individual interviews was used to gain access to the perspectives of patients about their experiences of participation in health care.<sup>34</sup> More specifically, a phenomenological approach was favoured in order to explore patients' experiences of participation across a variety of contexts and groups with the aim of "*describ[ing] the common meaning for several individuals of their lived experiences of a concept or a phenomenon*".<sup>35</sup> Prior to meeting participants, the researcher engaged in the practice of bracketing to reflect upon her experiences and views of participation in medical consultations, in order to set them aside to remain open to participants' experiences and their interpretations.<sup>35</sup>

### **Participants**

To be eligible, participants had to a) be 18 years of age or older, b) have consulted a physician in Québec-City in the past 12 months, and c) be able to speak French or English fluently. Efforts were taken to recruit participants from diverse ethnolinguistic backgrounds, to explore variations in participants' experiences of participation.

In accordance with the principle of diversification,<sup>35-37</sup> there were no exclusion criteria regarding context of consultations (e.g. type of concern, physicians' area of expertise, language of the consultation), in order to allow us to achieve a better understanding of general trends that emerged across a variety of contexts.

### **Procedure**

After ethics approval was obtained from the Research Ethics Committee at Laval University, we implemented a purposeful sampling strategy for recruitment. We paid particular attention to recruit a diversity of participants according to gender, education, and age, as these variables could possibly interact with ethnolinguistic status to shape experiences and perceptions of patient participation. We aimed to recruit participants until saturation was reached among participants who were born in Canada or abroad and among French speakers and non-French speakers: no more themes emerged after 60 interviews.

We used several recruitment strategies. First, we sent an email to the Laval University student and staff mailing list inviting eligible participants to take part in the study, which reached mostly university-educated participants. To reach participants from diverse ethnolinguistic background, we also contacted family medicine units, community healthcare centers, and local community centers. A call for participation was posted in these centers inviting potential participants who showed an interest in the study to contact the first author. Finally, we used the snow-ball technique to reach more participants, preferably participants who did not have a post-secondary education. More precisely, after interviewing participants, we asked them to talk about this study with friends and relatives. Those who were interested in sharing their experiences were invited to contact the first author to arrange a place and time for the interview. Volunteers contacted the first author to confirm eligibility and to set up a meeting at a time and location most convenient to them. Most interviews were conducted in a private office on campus, however, some participants preferred to meet in their homes, workplaces, or hospital rooms.

After participants' written consent was obtained, they completed a sociodemographic questionnaire and took part in an in-depth semi-structured individual interview. Interviews were conducted in the winter and spring of 2015 by a bilingual (English/French) researcher trained in qualitative methods (RR). Participants were free to do the

interview in French or in English. The interviews were audio-recorded and lasted on average 50 minutes (ranging from 24 to 123 minutes).

The interview guide focused, more generally, on patients' experiences of consultation with physicians. This general focus was chosen, to avoid biasing participants towards the topic of patient participation. To begin, participants were asked to describe a recent consultation experience with a physician. The open-ended nature of the introductory question allowed participants to describe their experiences in detail, while relating topics that were most important to them.

After having explored one experience in detail, participants were asked to discuss other consultation experiences. When participants stopped speaking freely, we probed with semi-structured questions, for three pre-identified themes, namely, positive and negative experiences, and perceived consequences of these experiences. Participants received \$20 in appreciation of their time.

The interviews were transcribed verbatim by a bilingual researcher, and the transcripts were checked for accuracy before being imported into NVivo 10.<sup>38</sup> Interviews were transcribed and analyzed in the language they were conducted, as the researchers analyzing the data were fully bilingual.

### **Analyses**

The first step of the analyses consisted of identifying and coding passages in which participants were describing a behaviour that represented "*taking an active part in their consultation*".<sup>3, p. 1299</sup> The next step consisted of an inductive content analysis to identify emerging themes. Narrow codes were first created and later organized into overarching categories. A codebook was developed to capture these narrow and broad thematic categories. The content of each category was further analyzed to provide rich descriptions of their content and to expose nuances.<sup>39</sup>

To ensure reliability, the codebook was developed conjointly by the first two authors (RR, AL), using the first six interview transcripts, which represent 10% of data. The first author coded the other 54 interviews. When new themes emerged in these interviews, the two authors met to discuss how to integrate them in the codebook. When disagreements occurred, the third author (YL) was consulted to resolve the disagreement.

To identify variations in experiences by place of origin and linguistic status, we ran matrix queries in NVivo 10<sup>40</sup> to compare the number of sources and references made to each code. First, we compared themes raised by

participants according to their fluency in French, as self-reported by participants in the sociodemographic questionnaire. Three groups were formed according to this criterion: 1) fluent in French as first language, 2) fluent in French as additional language, or 3) not fluent in French. Second, we compared experiences according to place of origin, as self-reported in the sociodemographic questionnaire. Two groups were formed according to this criterion: 1) born in Canada, and 2) born outside of Canada.

In addition to comparing frequencies of themes, we also paid special attention to passages in the text where participants referred explicitly to the influence of their ethnolinguistic background on their experiences of participation. Coding queries were then used to explore how themes were discussed according to ethnolinguistic background.

## Results

### *Participant Characteristics*

Sixty participants took part in this study (see Table 1). Approximately half ( $n = 33$ ; 55%) were female, and most participants ( $n = 38$ ; 63%) had a university degree. A little over half ( $n = 35$ ; 58%) were born in Canada. Most participants reported speaking French fluently, either as a first language ( $n = 26$ , 43%), or as an additional language ( $n = 25$ , 42%). It should be noted that some participants who reported speaking French fluently as an additional language, described having gained fluency after their arrival in Québec, and therefore also recounted some experiences of consultations in which they encountered linguistic barriers.

### *Experiences of Participation*

All participants discussed more than one experience of consultation with more than one physician. Contexts of consultations varied according to the type of concerns (e.g. mental health, pregnancy, annual check-up, acute or chronic problems), physicians' areas of expertise (e.g. specialist, resident, family doctor), and type of healthcare facilities (e.g. hospital, walk-in or family medicine clinic).

Although patients were not questioned explicitly about their participation, they spontaneously discussed the idea that they played a role in the consultation, and that the outcome of the consultation depended, partly, on their actions. Five major themes encompass the essence patients attributed to their experiences of participation (see Figure 1 and Table 2). These themes are presented in order of frequency, from most common to least common. We organized these themes into two central dimensions of patient participation: 1) information exchange, and 2) assertiveness.

**Table 1. Participants' sociodemographic information (N= 60).**

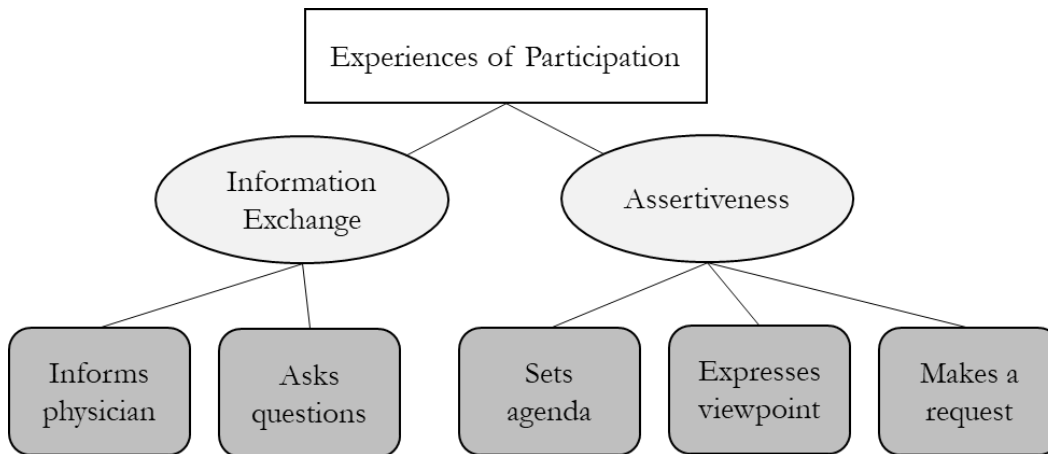
	F (%)
<b>Gender</b>	
Male	27 (45%)
Female	33 (55%)
<b>Age M (SD, range)</b>	41.6 (12.5, 19-73)
<b>Education</b>	
University	38 (63%)
< University	22 (37%)
<b>Language Fluency</b>	
French as first language	26 (43%)
French as additional language	25 (42%)
Not fluent in French	9 (15%)
<b>First Language</b>	
French	26 (43%)
English	20 (33%)
Other (e.g. Spanish, Mandarin, Portuguese, Japanese, Arabic, etc.)	14 (23%)
<b>Birth Place</b>	
Canada	35 (58%)
Outside Canada	25 (42%)
Africa	9
South and Central America	5
Europe	4
United-States	3
Asia	3
New Zealand	1

It became apparent that there were different levels of participation, according to who initiated the participative behaviour. At times, the patient initiated the behaviour, while at other times it was the physician who invited the patient to participate. Therefore, for each theme, passages were coded according to proactive (i.e. initiated by patient) or responsive (i.e. invited by physician) participation (see Figure 2). As depicted in Figure 2, instances of proactive participation were more commonly discussed by participants, followed by responsive participation. Besides, most instances of responsive participation involved physicians inviting patients to provide information regarding their health.

It also became apparent that there were passages in which participants explicitly recounted not having participated actively. These passages were coded as non-participative experiences. Overall, experiences of non-participation were less common. Indeed, whereas all participants discussed experiences of participation, only 27 (45%) discussed experiences of non-participation.



**Figure 1. Summary of the five major themes of patient participation according to the two dimensions of participation**



**Figure 2. Summary of the five themes of patient participation and frequency, according to two levels of participation (i.e. proactive and responsive) and non-participation**

	Information Exchange		Assertiveness		
Type of participation	Patient informs	Patient asks questions	Patient sets agenda	Patient expresses viewpoint	Patient makes a request
Proactive					
Responsive					
Non-participative					

**Legend.** Theme discussed very frequently = / Theme discussed less frequently = / Theme discussed rarely = / If cell is left blank = theme not discussed.

Generally, participants reported being more satisfied with consultations in which physicians showed openness to patient participation. Benefits of participating included feeling reassured, having a better understanding of their illness and treatment, and being able to make an informed decision.

*“I sought help from a doctor to have antidepressants. I met with a wonderful woman, who let me talk, who accompanied me, and who explained everything in detail. She showed me the DSM 5 so we could look at the factors together, so I could form an opinion on all*

*that. I participated in the diagnosis, which I really appreciated.”*  
Female, 25, France, French as first language

In contrast, they generally reported negative feelings when they did not feel their participation was welcomed by the physician in the consultation. For instance, they reported feeling misunderstood, disappointed, confused about their condition, having doubts about the treatment, and at times, not adhering to treatment when physicians did not show openness to patient participation.

**Table 2. Summary of themes and examples of quotes, according to the type of participation (proactive, responsive, or non-participative).**

	Proactive Participation	Responsive Participation	Non-participative
Patient informs	<i>“When I went for stitches, I told the doctor, I said I have allergies. She said: Allergic to what? So I named the list of my allergies.”</i> F, 31, Brazil, French AL <sup>1</sup>	<i>“She’ll [the doctor] work at it slowly. We’ll talk and when she sees that I’m not really comfortable, she’ll change the topic, and then she’ll come back will ask again. So in the end, I tell her everything, but it may take some time.”</i> M, 27, Canada, French FL	<i>“There’s some things I don’t even tell him because I don’t wanna get speecbed, because I’m vegetarian and my children are too and I don’t even tell them, because I’m not comfortable, and I don’t want to have to defend my point of view.”</i> F, 35, Canada, French AL
Patient asks questions	<i>“He instantly prescribed me a medication. He said: There you go. And off you go, kind of. When I asked questions, he answered. But if I hadn’t asked questions, he would’ve given me the prescription, but no explanations.”</i> M, 22, Canada, French FL	<i>“Then she’d ask me if I had questions (...) I understand now that I have to prepare my questions to be ready to ask them when she asks me.”</i> F, 24, Tunisia, French AL	<i>“I was disappointed that he didn’t explain, but I didn’t push for explanations. I could see he was in a hurry and it didn’t seem like he was interested to talk about it anyway.”</i> M, 29, Canada, French FL  <i>“When I’m with a doctor, it’s all about obedience. Yes, I will say what I feel and where it hurts, so I can be treated. But I have a lot of difficulty asking questions.”</i> M, 43, Rwanda, French FL
Patient sets agenda	<i>“I turned 50 this year and I had seen advertisements on TV and in magazines that vaccines against Zona were recommended when one turns 50. So I raised this issue with her to see what she thought about that, and if it was a good idea.”</i> F, 50, Canada, French FL	<i>“He takes the time to ask me how I am, and he’ll also ask me if there’s something else I’d like to discuss today. At that moment, if I have other concerns that I want to ask about, I’ll do it.”</i> F, 55, Canada, French FL	
Patient expresses viewpoint	<i>“I have been courageous enough to share my beliefs and she is open, and she really understands me in the way that I am very alternative, and she will if there is a situation for example I had a cyst on an ovary and she said that maybe we should do something. I said well, I have sort of a plan alternatively.”</i> F, 55, Canada, French AL  <i>“I saw a neurologist and he wanted to do a short intervention and I asked him to explain what he wanted to do. At first, he said: Listen, I’m a specialist, you just have to trust me. So I said: Sir, I’m a researcher and I have hypotheses, and it’s my body and there are things I know about my body that you don’t know. And if I don’t tell you these things, they can’t guide you.”</i> F, 61, Canada, French FL	<i>“I feel like she’s more collaborative. Because she’ll ask me how I feel about this option, because we were supposed to change my medication after Christmas, and she asked me what I thought about that.”</i> F, 26, Canada, French FL	<i>“When it’s not something vitally important, then I feel that I can’t really express it. When you don’t speak a language well, it’s hard to be subtle, you end up saying things stronger than you mean it.”</i> M, 30, New-Zealand, No French AL  <i>“I don’t even try to express my ideas. Like our pediatrician for my daughter, he’s a great example, because he’ll just shut you down before you even finish your sentence.”</i> F, 35, Canada, French AL  <i>“When that happened, I couldn’t do anything about it. Because back home, when a doctor says something and you say something else, he’ll just ask you: Are you a doctor? So you should just stay quiet.”</i> M, 30, Congo, French AL
Patient makes a request	<i>“I asked her if she was willing to have me go for food allergy tests and thank you for listening to me and I found out I had a lot of food allergies.”</i> F, 26, United-States, No French		

*“Then I started providing information about my diet to inform him as best as I could. And that’s when he said: Stop, I just want to know about the medication you take. He said he was the specialist and he knew best. I was really disgusted. I said ok fine, ask your questions and I’ll answer. But I wasn’t happy at all.”* Female, 31 Brazil, French as additional language

## Dimension #1: Information Exchange

### *Patient informs*

The most common participative experience consisted of patients disclosing health-related information to physicians. Underlying this participative behaviour was the central idea that the outcome of the consultation (and the



recommended treatment) depended, partly, on the quality of the information patients provided to physicians. Patients therefore recounted being honest while disclosing information, even when sensitive or taboo topics were broached, describing their symptoms as best as they could, and providing information they thought could be relevant to the consultation (e.g., allergies, current medications, life context information such as stress, a recent move or divorce, etc.).

Patients equally described instances of proactive (e.g. initiating information) and responsive participation (e.g. answering the physicians' questions). In a few rare cases, some participants described non-participative experiences in which they withheld information from the physician (e.g. sexual orientation) or were not completely honest with the physician when disclosing information.

#### ***Patient asks questions***

The second most common experience of participation was the experience of asking questions. Patients asked questions to better understand their conditions, test results, procedures, treatment options and potential side effects. At times, they asked questions to palliate the perceived lack of information provided by physicians or to ask for clarifications. They also asked questions concerning alternative or more natural options.

Most instances of question asking were coded into proactive participation. In a few rare instances, participants described a responsive participation, in which the physician first asked them if they had any questions. Patients appreciated this experience, as it made it easier for them to ask their questions. In a few cases, participants also recounted not having asked questions they had in mind.

## **Dimension #2: Assertiveness**

#### ***Patient sets agenda***

In terms of assertive behaviours, patients described participating in the consultation by setting the agenda and by raising topics or concerns that were important to them. For instance, some patients explained that they made sure to discuss all their concerns, even if these concerns and topics were sensitive (e.g. mental health concerns) or went beyond the scope of the consultation. Patients also explained that they valued their health and that they had knowledge about courses of actions they could take to maintain their health (e.g. change lifestyle or health habits) or to prevent future illnesses (e.g. get the Zona vaccine, start prevention screening for breast cancer). Having these thoughts prior to the consultation, they wanted to further discuss these matters with their physicians, so they broached these subjects during the consultation.

These experiences were mostly proactive but were sometimes also discussed in terms of responsive participation.

#### ***Patient expresses viewpoints***

Patients described expressing their preferences, values, and opinions about various topics (e.g. treatment options, natural or alternative options) with different degrees of assertiveness. Some patients simply expressed their agreement with their physicians' suggestions, others elaborated on their viewpoints and preferences with more details, and others disagreed with their physicians and expressed their differences in opinions or their refusal of the proposed treatment. At times, when patients felt their perspective was dismissed or not considered, some advocated for their experiential knowledge to be recognized. They felt their physicians needed to take their personal circumstances into consideration to find more appropriate options.

These experiences consisted mostly of proactive participation, as patients took the initiative to express their viewpoints or insisted on being heard. However, at times, it was responsive participation with physicians asking for the patients' viewpoints. In a few rare instances, some patients recounted non-participative experiences in which they had a certain opinion or preference, but they did not share this information with the physician.

#### ***Patient makes a request to the physician***

Patients had an idea of what they needed or wanted, and they described making various requests to their physicians. For instance, some patients requested a specific test or treatment, others asked physicians if they would accept them as their patients, requested legal documents to be filled (e.g. work injury, sick-leave, etc.), or requested alternative medicine or more natural options. These experiences were exclusively discussed as proactive participation.

#### ***Patient participation: Patients' rationale***

Particular attention was paid to passages in which patients shared their rationale for participating. A central reason for participating was that patients valued their health and took responsibility for it, as they understood that the outcome of the consultation partly depended on their actions. For instance, they wanted to inform their physicians as best as they could, and they wanted to understand their illness and treatment options, in order to select a treatment course that fit with their preferences and life context.

Patients also discussed various reasons for non-participation. Some did not feel comfortable with their physicians and feared being judged or scolded if they expressed certain viewpoints. Others felt rushed and felt that their physicians were not very open to them asking questions and expressing concerns. At times, patients

limited their participation since they did not have enough knowledge about the health issue being discussed. Finally, some patients discussed being too intimidated to participate, by fear of offending the physician.

### ***Variations by Place of Origin and Linguistic Status***

In response to the second research objective, themes discussed by participants were compared according to place of origin and linguistic status. A particular attention was paid to passages in which participants explicitly described the influence of their linguistic or ethnic background on their experiences of participation.

#### Variations by Linguistic Status

Variations emerged according to linguistic status. More precisely, participants who speak French fluently (as their first language or as an additional language) discussed the themes of asking questions and expressing their viewpoints more frequently, compared to those who do not speak French fluently. It should be noted that although only nine participants (15%) reported not speaking French fluently at the time of the interview, others also described experiences of consultations in which language barriers were an issue, since these participants gained fluency after their arrival in Québec. During the interviews, many participants described that facing a potential language barrier in the medical consultation hindered their participation.

*“I think what’s most difficult is communicating frustrations or upsetness, whereas in English, I would be more outspoken about it, because it’s more comfortable. In English I would say: I’m not so sure about that, and I’d give them my opinion, I’d be firm or would ask more pointed questions. Whereas in French, I’ll swallow a lot more before I go there.”* Female, 26, Canada, French as additional language

Interestingly, participants who had English as a first language discussed the influence of their linguistic identity on their participation in a different manner than participants with a first language other than French or English (e.g. Spanish, Mandarin). For English-speaking participants, sociohistorical tensions between Francophones and Anglophones in Québec seemed to partly explain their experiences. These participants (whether they spoke French as an additional language or not) were well aware of these tensions and they discussed their influence in their daily life, as well as experiences of discrimination according to their linguistic identity in medical consultations.

*“At one point my father in a very cheerful way mentioned that he didn’t have good French. But the doctor never spoke any English throughout and was sullen about the fact that my father had no idea what he was saying. (...) To bring something that sounded frankly*

*political into a health care context, I thought was offensive.”* Male, 42, Canada, No French

#### Variations by Place of Origin

One variation emerged according to place of origin. Findings revealed that participants born in Canada discussed setting the agenda more frequently (e.g. raised more concerns). However, contrary to the influence of linguistic identity, explicit references to participants’ cultural background and its perceived influence on patient participation were rarely discussed.

## **Discussion**

This study aimed to explore patients’ experiences of participation in medical consultations with physicians, and to explore potential variations in patients’ reported experiences according to their places of origin and linguistic status.

### ***Experiences of Participation***

Five key observations emerged in response to the first research objective (see Table 3). First, patient participation spontaneously emerged during the interviews, although participants were not explicitly prompted to discuss this topic. This observation suggests that from the perspective of patients, participation is an integral component of their healthcare experiences.

Second, although they discussed both participative and non-participative experiences, participative experiences were much more frequently evoked by participants. In fact, all participants described experiences of participation, whereas only approximately half discussed non-participative experiences. This finding illustrates that patients perceive themselves as active participants in the consultation.

These observations may be explained in terms of the value participants placed on their health. Indeed, participants often described that they value their health and they take responsibility for it. Therefore, they believed it was important to participate in medical consultations, as their health could be affected by the outcome of the consultation. The broader sociocultural, North American context may partly explain this finding, since it is one that greatly values individualism and, in turn, health autonomy.<sup>41</sup> As a result, the responsibility for health is mainly attributed to individuals, as health is believed to be affected by personal behaviours and lifestyle choices.<sup>41</sup>

Third, participants generally expressed greater satisfaction with consultations in which physicians showed openness to patient participation, whereas they expressed disappointment, frustration, or other negative feelings with regards to experiences in which there was little to no room for them to participate. This finding echoes results from

previous studies revealing a link between patient participation and patient satisfaction and adherence,<sup>7,19</sup> thus suggesting that patients in this study gained benefits from participating in the consultation. Future research should explore contexts in which patients report experiences of non-participation to better understand potential facilitators and barriers to participation. These factors could be the targets of future interventions aimed at fostering patient participation.

Fourth, five themes of participation emerged and were categorized in two key dimensions. The first dimension relates to participation in terms of information exchange and encompasses two themes: informing the physician and asking questions. This dimension aligns with findings of a previous study investigating patients' perspectives on participation in handover between primary and secondary care.<sup>42</sup> The second dimension relates to participation in terms of assertiveness and encompasses three themes: raising one's agenda, expressing one's viewpoint, and making a request.

These findings suggest that patients have a broad perspective of their participation in consultations, as the experiences they reported extended further than the decision-making process. This finding contrasts with some previous studies in which patient participation was reduced to decision-making.<sup>12</sup> This observation emphasizes the need to extend the concept of patient participation and to develop a broader framework.

Since the present study was exploratory in nature and did not explicitly question participants about their experiences

of patient participation, more research is needed to explore whether there are other key dimensions to patient participation, across a diversity of patients. That said, the two key dimensions of patient participation that emerged align with components of patient participation used in a previous discourse analysis coding system.<sup>15,43</sup> This observation suggests that this coding system captures well key dimensions of patient participation from the perspective of patients.

Fifth, the present findings expand on the work of Peräkylä and Ruusuvuori<sup>16</sup> who distinguished between proactive and reactive participation only on one of their five components of patient participation. We observed these two levels of patient participation across all five themes that emerged. This distinction is key as it emphasizes the relational nature of patient participation. Indeed, when patients described instances of responsive participation, they explained how their participation was dependent on the physicians' behaviours (e.g. physician asking their preferences).

This observation suggests patient participation does not solely depend on patients and that physicians can play a more active role in setting the tone for patients to participate. Some patients expressed the desire that their physicians initiate and facilitate their participation (e.g. physician could ask about patients' preferences, instead of the patient having to ask for natural options). Health professionals should remain sensitive to their role and could take more initiative to facilitate patient participation. These observations have both conceptual and practical implications. They suggest the need to revisit definitions of

**Table 3. Summary of key findings**

<b>Key Findings</b>	
<b>Patients' Experiences of Participation</b>	
1.	Patient participation spontaneously emerged as central theme of patients' experiences of consultations
2.	Participative experiences were raised much more frequently than non-participative experiences
3.	Patients expressed being more satisfied when their physicians showed openness toward their participation
4.	Patients had a broad view of their participation and two central dimensions of patient participation emerged: 1) information exchange, 2) assertiveness
5.	Two levels of participation emerged according to whom initiated the participation: 1) responsive participation and 2) proactive participation.
<b>Variations in Patients' Experiences of Participation</b>	
6.	Language fluency and linguistic identity seems to be a key influence on patient participation

patient participation, to make them more relevant to the experiences of patients.<sup>20</sup> Building on Thompson's<sup>3</sup> work, we suggest the following definition of patient participation: "patients taking a proactive or responsive part in terms of information exchange and assertiveness in their consultations with professionals". The two dimensions and the two levels of patient participation that emerged in this study represent a way to operationalize patient participation which could guide future research, as well as interventions promoting patient participation.

#### ***Variations by Place of Origin and Linguistic Status***

Variations emerged in experiences of participation according to linguistic status. Findings suggest that language fluency is a key prerequisite for patient participation, as participants who did not speak French fluently raised fewer participative experiences. These participants often explicitly described how difficult it was to fully participate, given they had difficulties communicating in the language of the consultation. This was the case for English-speaking participants born in Canada as well as participants born outside of Canada and who were not fluent in French. This finding aligns with previous research that revealed that ethnic minority patients who speak the language of the majority fluently participate more than those who face language barriers.<sup>18,25,44</sup>

These findings support the notion that patient participation is a communicational process,<sup>15</sup> and they highlight the importance of overcoming language barriers in order to facilitate patient participation. Future research should also explore patient participation in the context of interpreted consultations.

With regards to place of origin, findings show that participants born in Canada more often reported setting the agenda. This variation may be due to participants' representations of health and/or of their roles as patients. Nevertheless, we are cautious when interpreting these findings, as participants rarely explicitly discussed the influence of their place of origin on their experiences of participation.

Although language probably represents a key element of patient participation in all contexts, it is possible that in the context of Québec-City, more specifically, language competency and linguistic identity becomes particularly salient. Indeed, previous research has shown that language is a key aspect of Canadians' collective identities.<sup>45,46</sup> Moreover, tensions have long defined the relationship between the French-speaking and the English-speaking populations in Québec, which can permeate the medical context and have repercussions on the physician-patient relationship. These contextual influences may explain why English-speaking participants discussed the influence of

their linguistic status in different terms than participants with a first language other than English or French.

#### ***Strengths & Limitations***

This study made a contribution to the existing literature of patient participation by exploring in-depth patients' experiences of participation in medical consultations, while exploring potential variations according to linguistic backgrounds and places of origin. A strength of this study is that patients were not directly probed about their experiences of participation in the consultation, but this theme emerged spontaneously. This suggests that patient participation is a key component of patients' experiences of healthcare consultations.

A limitation of this study relates to our participants' education and cultural backgrounds. First, participants had a high level of education. Their perceptions of participation may differ from participants without postsecondary education.<sup>5</sup> Second, the variety of cultural backgrounds limits our interpretation of findings concerning differences in participation according to places of origin. Future studies should explore ethnic minority patients' definitions and conceptualization of patient participation across a homogeneous group of patients, to further understand the role of language and culture in patient participation.

#### ***Conclusions***

In conclusion, findings show that patients perceive themselves as active participants in medical consultations with physicians. Overall, participants had a more positive evaluation of experiences in which they participated in the consultation, thus suggesting that patient participation is valued by participants. Patients described two levels of participation (i.e. proactive and responsive), and they described five participative behaviours categorized in two key dimensions (i.e. information exchange and assertiveness). These findings suggest that the concept of patient participation should be expanded beyond participation in decision-making. Finally, language fluency and linguistic identity seemed to be a key influence on patient participation.

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