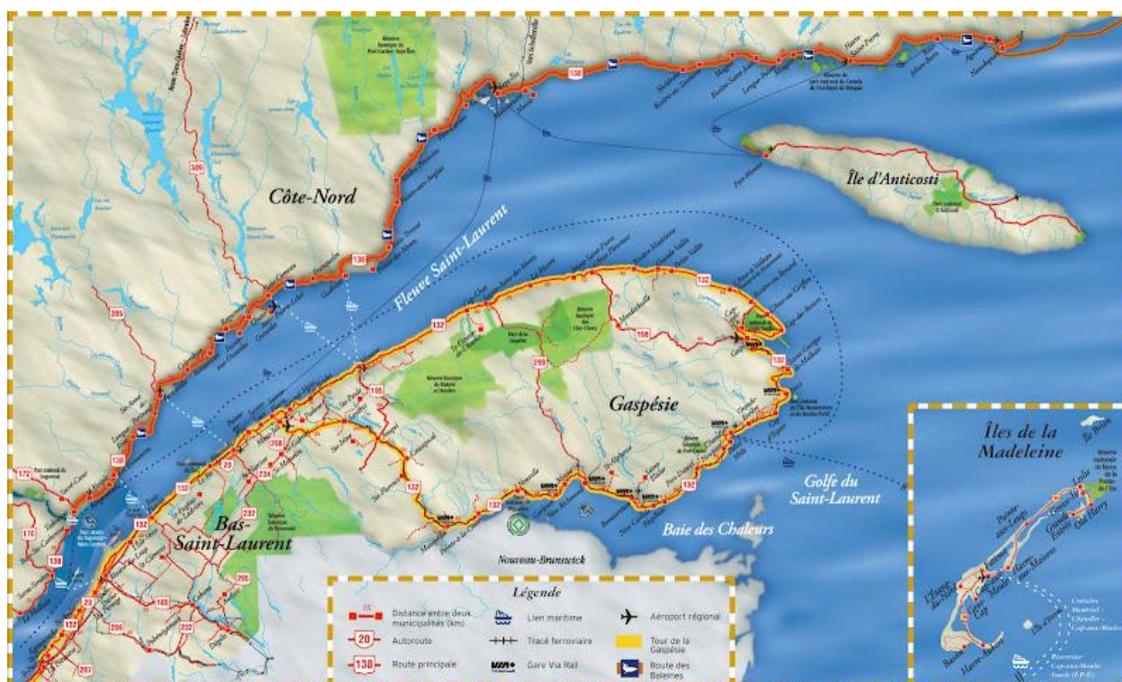


Inter-Regional Access to Specialized Health and Social Services for English-Speakers from Eastern Quebec



6/30/2015

A needs assessment

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Inter-Regional Access to Specialized Health and Social Services for English-Speakers from Eastern Quebec

A needs assessment

CONTEXT

In Quebec's health care system, some services are available locally (in health centres, clinics or private offices) while other treatments are available only in specialized institutions, located most of the time in urban centres. Residents of rural and remote regions therefore have to travel to these centres to receive certain specialized health care, most often to Quebec City, Montreal or a smaller city such as Rimouski (in the case of Gaspésians), Sept-Îles or Chicoutimi (in the case of residents of the North Shore).

This project was developed to better understand the experience and needs of English speakers from the eastern regions of Quebec (Gaspésie - Îles-de-la-Madeleine, the North Shore, including the Lower North Shore, and the Lower Saint-Lawrence) as concerns extra-regional health and social services. The specific challenges facing this official language minority community were known only anecdotally, but needed to be better understood before effective action could be taken to address the needs of this population.

Two separate but interconnected projects are underway in relation to this theme. One is managed for the Agence de la santé et des services sociaux for region 11 and its *comité régional sur l'accessibilité aux services en langue anglaise* by the Committee for Anglophone Social Action (CASA), in collaboration with the Council for Magdalen Islanders (CAMI), Vision Gaspé-Percé Now (VGPN) and Heritage Lower Saint-Lawrence. The second project is being carried out by Jeffery Hale Community Partners (JHCP), focusing specifically on the needs and challenges of English speakers from all of the eastern regions of Quebec who travel to Quebec City for specialized health services. These projects will contribute to concerted actions to address some of the main issues revealed by the research, by engaging either public institutions or community resources in Quebec, the city that receives the greatest proportion of patients from the Eastern regions. Funding was provided by Health Canada through the CHSSN for adapting services to the needs of official language minority groups.

STUDY APPROACH AND METHODOLOGY

The project objectives are threefold:

1. To better understand the situation and experience of English-speaking Quebecers from the eastern regions of the province regarding extra-regional services
2. To identify the main challenges facing them as they travel to and stay outside their region of residence
3. To identify approaches to address these challenges, in collaboration with priority health institutions and community organizations

In order to reach these objectives, a participatory action research approach was used and a data collection strategy was developed, as described below.

Participatory action research

The approach being taken for these projects is rooted in community-based participatory action research. This means that the research is being done with and by the “community”—in this case, community organizations representing and serving English speakers—in response to the needs of community members, with the goal of taking action on issues affecting these communities.

Participatory and action research both have a long history, having been developed by educators, community development workers, sociologists and anthropologists in an effort to connect research more closely with real life issues. The process (and ultimate goals) include empowering people to produce valuable knowledge on issues that affect them by including and engaging the beneficiaries, stakeholders and users in the research process and in identifying ways to take action (Cargo & Mercer 2008; Minkler & Wallerstein 2008; Israel et al., 2013).

In the project described here, the objective was to gather valid quantitative and qualitative information on the situation and, in doing so, to build the capacity of community leaders to conduct such research and use it to engage with partner organizations in identified actions. The two research consultants involved in various steps of the projects supported the project coordinator and others, as needed, in order to reach these objectives.

Methodology

Survey conducted by regional associations

In order to gather data from a representative sample of English speakers in the eastern regions, the first step was to develop a survey to be distributed among English speakers in the Gaspésie-Îles-de-la-Madeleine, the Lower Saint-Lawrence, the North Shore and the Lower North Shore. The

survey contained questions about the use of services close to home, experience with services outside the region, travel and refund issues, and more. In each case, questions assessed what services respondents have accessed, how they communicate with health personnel, whether they receive assistance, what written documents were provided to them, and more.

The sample sizes for each territory were calculated using a confidence level of 95% and a confidence interval (margin of error) of 5. Using this target sample size along with the 2011 data available through Statistics Canada for each MRC, the targeted respondent distribution was developed.

A total of 847 surveys were filled out between November 2014 and April 2015. The distribution of respondents is shown below. Several different distribution methods were used, depending on the region. In some areas, at gatherings where English speakers could be found (for example, wellness centres for seniors, events in local communities, schools and more), the project coordinators went in person and encouraged attendees to fill the survey out, providing help when needed. In another area, an employee made appointments with residents and went to people's homes to complete the survey with them. This ensured that the survey would be filled out, taking into account project timelines and varying levels of literacy. In another area the survey was distributed online.

Region	Target	Number of respondents
Gaspésie-îles-de-la-Madeleine	370	344
Lower Saint-Lawrence	292	205
North Shore + Lower North Shore	132 224	298
Total	1018	847

Statistics from health care institutions

An additional source of quantitative data was provided by local CSSS: this was the numbers of persons transferred out-of-region, by specialty, in 2013-2014. Although these numbers were not broken down by language (mother tongue or language most used at home), they could be used to estimate approximate numbers of English speakers leaving the region for specialized services, assuming they are transferred at similar rates per capita as Francophones (and there is no reason to think they are not).

Focus group discussions

A focus group discussion outline was developed for conducting a number of discussions with groups from across the GIM region only (on the Magdalen Islands, on the tip of the Gaspé, and on the Baie-des-Chaleurs territory). These discussions were facilitated by the coordinator and a

research consultant, as the case may be. The discussions were all held between January and March 2015.

These discussions made it possible to hear people’s experiences accessing health services outside their region of residence. The participants included people who had been patients themselves, as well as people who had accompanied a friend or loved one as a support person. Topics discussed included the situation for which they were transferred or accompanied another person, preparations for the trip, the challenges of being away from home (often in a new environment), communications with health care staff, their support network, any written information they were given or needed, the discharge process, travelling back home, and suggestions for changes that might make the experience easier.

A total of 13 focus group discussions were held with between 4 and 10 participants per group. They were held in a public space such as a school, a community organization office, a community centre or other.

Community	Participants
Gaspé	6
Gaspé	6
Gaspé	5
Grosse-Ile	7
Grosse-Ile	6
Grosse-Ile	8
Cascapedia	5
Port-Daniel	5
Matapedia	4
Escuminac	5
Barachois	9
Barachois	9
Cascapedia	10

Data analysis

An Excel spreadsheet was developed by a research consultant for the data entry. The surveys from all regions were centralized at CASA offices, and the data was entered by the same person for all the surveys, in an effort to eliminate mistakes that could be made by having different people in different regions do the data entry. Support from the research consultant was provided to deal with any difficulties or questions. A random sample of surveys was checked for mistakes and any corrections needed were made.

An initial tabulation was completed by the consultant, and tables were created to show the values for the different variables. This step made it possible to do an initial descriptive analysis. Already at this phase, certain patterns emerged and issues could be identified. Then, cross-tabulations of specific variables were completed to focus in on specific issues and situations in different cities and institutions.

As concerns the focus group data, a thematic analysis was completed, which made it possible to highlight a broad range of experiences, as well as some of the most common challenges faced by inter-regional patients.

FINDINGS

In this report, we present only the data from respondents who have travelled to Quebec City for specialized services. Please note that data is also available separately for the entire group of respondents regardless of place of treatment.

Among all survey respondents, approximately 65% had travelled out-of-region for health services, 35% for themselves, 17% to accompany a spouse, family member or friend, and 9.8% as both a patient and a caregiver; 35% of respondents had not travelled out of the region for health care services.

Among those who had travelled out of their region of residence for services, almost half had been transferred to Quebec City, with 16% going to Montreal and 17.7% to Rimouski. Almost half had been to other locations as well (Sept-Îles, Chicoutimi).

Socio-demographic and linguistic characteristics of respondents

A total of 167 respondents have travelled only to Quebec City (and not to more than one place). It is this sample that we analyze here. In this group there were 110 women and 57 men. Almost half were 61 years of age or more. This is important to bear in mind when considering actions, since many patients are seniors and may need other types of support in addition to assistance with language.

Table 1: Sociodemographic data

	(n= 167) n (%)
Sex	
<i>Female</i>	110 (65,9)
<i>Male</i>	57 (34,9)
Age group	
<i>18-35</i>	20 (12,0)
<i>36-45</i>	26 (15,7)
<i>46-60</i>	42 (25,3)
<i>61+</i>	78 (46,9)
Mother tongue	
<i>English</i>	152 (91,6)
<i>French</i>	3 (1,8)
<i>Both</i>	9 (5,4)
<i>Other</i>	2 (1,2)

Almost half of respondents are 61 years of age or older.

In this group, almost 90% of respondents are most comfortable in English when speaking to a health services provider; about 4% are most comfortable in French; and 6% are fluent (see below).

Table 2 – When talking to a health provider, what language are you most comfortable in?

	(n= 167) n (%)
<i>English</i>	149 (89,8)
<i>French</i>	7 (4,2)
<i>Other</i>	10 (6,0)

Almost 90% are most comfortable in English when talking to a health care provider.

When receiving health services, about 40% speak only in English; about 25% say they can get by in French, but not when it comes to technical health / medical terms; 17% say they try to get by in French, but don't always know what is being said or what they are reading; and about 11% are perfectly bilingual. This means that 57.5% are unable to fully understand information when talking to service providers in French and a total of 83% are not proficient enough in French to understand more technical discussions involving medical terms. Some respondents commented that they prefer English even if they do understand French. One mentioned that medical personnel are very willing to help them understand.

Table 3 – Which statement best describes your situation when receiving health services?

	(n= 167) n (%)
<i>I only speak English</i>	67 (40,1)
<i>I can get by in French, but not when it comes to technical health / medical terms</i>	43 (25,7)
<i>I try to get by in French, but I don't always know what is being said or what I'm reading</i>	29 (17,4)
<i>I am perfectly bilingual and don't have a preference for French or English</i>	19 (11,4)
<i>Other</i>	9 (5,4)

A total of 83% are not proficient enough in French to understand more technical discussions involving medical terms.

As concerns written information, half of respondents consider it essential to receive this in English and another 34% consider it preferable. In the comments, several people pointed out that although

they understand French, they prefer English (one person specified that they understand the vocabulary better).

Table 4 – How important is it for you to receive written information / documents about your health in English?

	(n= 167) n (%)
<i>Essential</i>	84 (50,6)
<i>Preferable</i>	58 (34,9)
<i>Unimportant</i>	17 (10,2)
<i>Other</i>	7 (4,2)

Half of respondents consider it essential to receive written information in English and another 34% consider it preferable.

Why is this important? Levels of bilingualism may vary from one person to another, and many English speakers in Quebec are able to communicate in French, to varying degrees. However, for the purposes of health care, the level of bilingualism may not always be sufficient. Research has shown that language barriers in the health care encounter can result in less-than-optimal use of the health care system, for example, poor use of preventive services and over-use of acute care. It can also lead to communication difficulties, which may result in inadequate assessment, lower patient understanding of diagnosis and treatment and decreased patient confidence and satisfaction, for example (Bowen, 2004).

Communicating with health care staff while out-of-region

Survey questions concerned two forms of communication: verbal communications with health care staff and written communications. We also discuss alternative strategies for dealing with communications issues, as developed by patients and their loved ones.

Verbal communications

The survey data shows interactions with various categories of health care staff while out of region. The table below shows the results, with doctors and nurses being the people with whom patients were most likely to communicate. Doctors were the most likely to communicate fully in English (over 65%) or partly in English (almost 14%). Only 19% of nurses communicated fully in English or partly (over 28%), with a quarter not understanding English. Only 14.5% of admissions staff communicated fully in English and 20% partly in English, with a third not understanding English.

Table 5: Interactions with health care staff while out-of-region

	(n= 167) n (%)
TRANSPORTATION STAFF	
<i>Did not communicate with</i>	55 (36,9)
<i>Did not understand my English</i>	14 (14,9)
<i>Seemed to understand but replied in French</i>	8 (8,5)
<i>In part in English</i>	27 (28,7)
<i>Fully in English</i>	34 (36,2)
<i>Other</i>	11 (11,7)
ADMISSIONS STAFF	
<i>Did not communicate with</i>	20 (13,2)
<i>They did not understand my English</i>	45 (34,4)
<i>Seemed to understand but replied in French</i>	22 (16,8)
<i>In part in English</i>	27 (20,6)
<i>Fully in English</i>	19 (14,5)
<i>Other</i>	18 (13,7)
NURSES	
<i>Did not communicate with</i>	3 (1,9)
<i>Did not understand my English</i>	41 (25,9)
<i>Seemed to understand but replied in French</i>	24 (15,9)
<i>In part in English</i>	45 (28,5)
<i>Fully in English</i>	30 (19,0)
<i>Other</i>	18 (11,4)
DOCTOR	
<i>Did not communicate with</i>	2 (1,3)
<i>Did not understand my English</i>	12 (7,6)
<i>Seemed to understand but replied in French</i>	4 (2,5)
<i>In part in English</i>	22 (13,9)
<i>Fully in English</i>	104 (65,8)
<i>Other</i>	16 (10,1)

Doctors were the most likely to communicate in English followed by nurses, with admissions staff being less likely to speak English.

*The "did not communicate with" answers are not included in the calculations.

In focus group discussions with residents of the Gaspésie-Îles-de-la-Madeleine region, several points were made. First, the greatest communications challenges were faced at reception and with nursing staff. Second there are great disparities in the levels of bilingualism among health care staff and the situation has changed over the years. Third, some of the stress or a feeling of inferiority is experienced when health care professionals appear to lack empathy for difficulties understanding or communicating.

In general, physicians speak English while nurses may or may not, and receptionists, orderlies and technicians generally do not. Many participants spoke of nurses finding another nurse on duty who could speak English, and people with long-term health problems who get to know the staff may ask specifically for a nurse who they know speaks English.

Several people had experienced negative attitudes and some were even told “you live in Quebec, you should speak English” or “I do not have to speak English”. However, as one person said, “I don’t think it’s always a discrimination thing, but I think the staff feel intimidated when they have to speak English to a patient, so maybe they avoid them”. In some cases, staff would try to do their best, and one person said they apologized for not speaking English. So the full range of attitudes and responses seems to be present.

Several participants noted that in their experience, communicating in English has become easier over the years. One person commented: “experience was fine, we appreciated the treatment by all medical staff. Both in English and French. I was surprised at how accommodating everyone was in Quebec and at how quickly they were willing to speak to us in English.” Another person commented: “A bit more communication in English would be very helpful.”

Others acknowledged that it is not always a question of language but that the “great big words” used for medical issues simply make it hard for many people to understand. One person who had received services in Ottawa, where English is the language of work, said “I didn’t realize what a difference it made until I got the services in English, a whole level of stress was gone”.

Written information

Written information may be important for decision-making, post-treatment care, understanding medication and providing consent, for example. When patients do not fully understand the choices and implications of treatments or its follow-up, health care may not be optimal and the experience is likely to be less satisfactory, at times, even dangerous. As shown in the table below, between 36% and 45% of written information was available in French only (either requested or not), while between 43% and 56% was provided in English.

Table 6: Description of the written information provided while out-of-region

	(n=167) n (%)
Disease-condition	
<i>This was not provided</i>	39 (27,9)
<i>In French only; did not request English version</i>	28 (27,7)
<i>Requested English version, but only available in French</i>	16 (15,8)
<i>After requesting, English version was provided</i>	22 (21,8)
<i>All was provided in English without being requested</i>	31 (30,7)
<i>Other</i>	4 (4,0)
Treatment Options	
<i>This was not provided</i>	36 (26,3)
<i>In French only; did not request English version</i>	26 (25,7)
<i>Requested English version, but only available in French</i>	11 (10,9)
<i>After requesting, English version was provided</i>	21 (20,8)
<i>All was provided in English without being requested</i>	37 (36,6)
<i>Other</i>	6 (5,9)
Side-Effects	
<i>This was not provided</i>	42 (32,8)
<i>In French only; did not request English version</i>	25 (29,1)
<i>Requested English version, but only available in French</i>	7 (8,1)
<i>After requesting, English version was provided</i>	22 (25,6)
<i>All was provided in English without being requested</i>	26 (30,2)
<i>Other</i>	6 (7,0)
Forms to fill out	
<i>This was not provided</i>	25 (17,9)
<i>In French only; did not request English version</i>	35 (30,4)
<i>Requested English version, but only available in French</i>	17 (14,8)
<i>After requesting, English version was provided</i>	23 (20,0)
<i>All was provided in English without being requested</i>	27 (23,5)
<i>Other</i>	13 (11,3)

Between 36% and 45% of written information was available in French only (either requested or not), while between 43% and 56% was provided in English.

*The "this was not provided" answers are not included in the calculations.

In the focus group discussions, participants agreed that in general written information is provided in French only. However, there were several exceptions where information on conditions and treatment was available in English. When participants requested an English version of a document the response was often "we don't have any right now" or "we are waiting to get some". One area of concern was consent forms, which often were provided in French only; several people said they did not really understand what they were signing. At the time of discharge, written information (for after-care or home care) seems to be entirely in French, and verbal instructions are given in English.

Table 7: Before returning home, was the following information provided?

	(n= 167) n (%)
Prescriptions	
<i>Not provided in either language</i>	25 (17,0)
<i>Only in French</i>	43 (35,2)
<i>Partly in English</i>	10 (8,2)
<i>Fully in English</i>	64 (52,5)
<i>Other</i>	5 (4,1)
Care for home (spoken instructions)	
<i>Not provided in either language</i>	19 (13,3)
<i>Only in French</i>	31 (25,0)
<i>Partly in English</i>	29 (23,4)
<i>Fully in English</i>	62 (50,0)
<i>Other</i>	2 (1,6)
Care for home (written instructions)	
<i>Not provided in either language</i>	36 (26,3)
<i>Only in French</i>	41 (40,6)
<i>Partly in English</i>	13 (12,9)
<i>Fully in English</i>	46 (45,5)
<i>Other</i>	1 (1,0)

When being discharged, about half of the written instructions for medication, after-care or home-care was provided fully in English. Between a quarter and a half was provided in French only.

*The “not provided in either language” answers are not included in the calculations.

Strategies for communicating

Many of the participants in focus group discussions reported the use of a support person (or caregiver) when travelling out-of-region. In some cases, these respondents had been the support person, while in other cases they had taken a support person with them. Anecdotally, this seems most often to be a family member who speaks French: a sibling, child, spouse or in-law. This person can help translate as well as provide general moral and physical support. One person said that after going to Quebec City alone one time, “the second time I got smarter and got somebody to take me. I wouldn’t ever go alone again”.

However, this incurs significant costs and can be a challenge due to the medical terminology and, at times, the sensitive nature and confidentiality of health care information. One woman said that she has always translated for her husband “but sometimes the technical terms, you don’t know how to say it”. Some people have accompanied loved ones so many times that they have become a sort of “expert” in dealing with the health care system. One person said “after doing it for 30 years I’ve got the hospital system figured out, but the first few times I spent more time in tears”. In some cases, religious institutions or *hôtelleries* can be helpful sources of support, some even having volunteers who will visit or pick people up. It is worth noting that none of the participants had ever encountered a professional interpreter (or been offered their services).

Health care provided in Quebec City

Patients are transferred to Quebec City for a range of medical specialities, to a number of different hospital centres.

Health conditions treated

Among the 167 respondents who have travelled to Quebec City for health care, about 32% did so for heart disease treatment; almost 23% for cancer treatment; and 12% for a pediatrics. Almost half of respondents answered "other" to this question. When analyzing the comments made, 16 referred to orthopedics (e.g., back problems), 6 were treated in neurology, 5 travelled for eye problems, 5 for cardio-pulmonary issues, 4 for gastro-intestinal problems, 3 for kidney disease, 2 for endocrinology and 2 for perinatal care. Surgery was also mentioned as well as emergency care, dentistry and psychiatry.

Table 8: For what type of health care was the out-of-region travel required?

	(n= 167) n (%)
Other*	66 (46,2)
Orthopedics	16
Neurology	6
Ophthalmology	5
Cardio-pulmonary	5
Gastro-intestinal	4
Kidney disease	3
Endocrinology	2
Perinatal care	2
Heart Disease	54 (32,5)
Cancer	38 (22,9)
Specialist for children	20 (12,0)
Hearing specialist	2 (1,2)

The most frequent types of health care received out-of-region were in cardiology, oncology, pediatrics and orthopedics.

Institutions most frequented

When asked where they received care, the most frequent answer was "other". Among the choices provided, 41 respondents were treated at Hôpital Laval, 37 at the CHUL and 30 at Hôpital Enfant-Jésus. In the comments made, it is possible to see that 30 respondents were treated at Hôtel-Dieu-de-Québec, 12 at Saint-Sacrement and 9 at Saint-François-d'Assise. When asked if the place of treatment was their first choice, 88% said yes and many of the others said that either they had no choice or it was the only choice. One person mentioned that they wanted to go to Montreal but were refused.

Table 9: In which hospital / center were the services received?

	(n= 167) n (%)
Other*	51 (30,7)
Hôtel-Dieu-de-Québec	30
Saint-Sacrement	12
Saint-François-d'Assise	9
Hôpital Laval	41 (24,7)
CHUL	37 (22,3)
Enfant Jésus	30 (18,1)
Don't know	7 (4,2)
First Choice?	125 (88,0)

Overall, Hôpital Laval is the most frequented hospital, followed by CHUL, Hôtel Dieu and Enfant-Jésus; however they each have close to one-quarter of the respondents.

Travelling to and staying in Quebec City

The survey data helps to paint a picture of the means of transportation used, the length of stay in Quebec, where people stay and what helpful information they were given.

Means of transportation

Most respondents travelled by car or plane to Quebec City. It is important to remember that those travelling from the Magdalen Islands, from the Lower North Shore or the North Shore have to fly, while those from the Gaspé Coast or the Lower Saint-Lawrence may be able to drive or take a bus.

Table 10: The out-of-region travel (to & from the hospital / center) was made by:

	(n= 167) n (%)
TO	
Car	71 (43,0)
Plane	65 (39,4)
Bus	20(12,1)
Other	6 (3,6)
Ambulance	2(1,2)
Train	1 (0,6)
FROM	
Car	74 (46,8)
Plane	65 (41,1)
Bus	12 (7,6)
Other	5 (3,2)
Ambulance	2 (1,3)
Train	0 (0,0)

Car and plane account for the vast majority of trips to Quebec City for health care services.

A few respondents mentioned that they were evacuated by air, used medical transport or adapted transport. For people travelling by plane (for example from the Magdalen Islands), an agent at the CSSS generally makes the travel arrangements for the patient. However, if a support person (caregiver) is travelling as well, that person has to make their own arrangements for travel as well as for accommodation. Information seems to come from many different sources, such as health institutions, regional associations, friends and family, and the receiving hospital.

In addition, when the patient is a child, the transfer process can be very difficult and stressful for the parents or caregivers, since they cannot accompany the child in the air ambulance. One respondent commented: "The only thing that was truly traumatic regarding this situation was having to place our under 2 year old son on the ambulance plane totally alone knowing we couldn't be at CHUL to receive him and that he would be alone for the many hours it took for me to join him in QC City." Another person commented: "Once getting to the CHUL and being admitted, things are usually fine but the transportation is the hardest part, particularly when my daughter went by jet. Getting to the hospital and trying to figure out if she arrived yet and where she was is always unorganized, hectic and scary."

For those travelling by public transportation, a decrease in bus and train services makes it more difficult to arrange for transportation. In focus group discussions, a participant from the Gaspé Coast said "I think the worst thing for seniors is that the train is gone, a comfortable and safe means of transportation for the winter". Others expressed frustration with the bus service, which they said you have to reserve 24 hours in advance.

Length of stay

About half of respondents stayed in Quebec City for less than a week, 27% stayed between 1 and 4 weeks, 8% made a day trip and 9% stayed longer than a month:

Table 11: How long was your stay?

	(n=167) n (%)
Day trip (not overnight)	13 (8,0)
Short Stay (less than a week)	86 (52,8)
Extended Stay (1-4 weeks)	44 (27,0)
Lengthy Stay (longer than a month)	15 (9,2)
Other	5 (3,1)

Most stays were less than one week, with another quarter lasting between a week and a month.

This information is important in understanding the challenges facing people from out of the region, since it has repercussions on many levels: it can pose a significant financial burden on individuals, families and communities; it means that people are likely to be alone while dealing with the stress of an illness (since caregivers are not always able to stay for a long time); and it means that the stress of all the various challenges is experienced for some time.

Accommodation in Quebec City

The table below shows where people stayed while away from home. Those who indicated “other” generally stayed at a bed and breakfast or in the hospital.

Table 12: Where did you stay while away?

	(n= 167) n (%)
Motel-Hotel	54 (35,5)
Hôtellerie (connected to hospital)	20 (13,2)
Religious Institution	11 (7,2)
Family member’s or friend’s home	14 (9,2)
Other	53 (34,9)

In some cases, the hospital provided information on where to stay in Quebec City; in other cases the regional organizations did so (CASA, CAMI, Coasters, VGPN, Heritage); in still others, people phoned friends and neighbours who had previously travelled to the same place for health services. This underscores the fact that information comes from several sources and that there are disparities among respondents regarding their level of awareness and access to information.

In focus group discussions, participants discussed the challenges in finding a place to stay while away, that is, when they were not admitted to hospital or when they were travelling as a caregiver. This is a significant source of stress, as it can take several calls to arrange and not everyone speaks English. In addition, finding affordable options proves stressful for many. This adds to the challenges that many feel in being in an unfamiliar environment, particularly when coming from a rural region to a large city that is unfamiliar for many. As one participant said “the scariest thing is when you go to the ‘big city’ and you’re just this little thing from the country”.

Once in the city, about half of respondents did not receive any helpful information where they stayed. Others received maps, restaurant information, taxi numbers, public transit schedules, directions to stores and other information. Some respondents commented that people were helpful or would have been if they had asked for help. Some also mentioned that they did not need information.

Table 13: Were you given any helpful information where you stayed?

	(n= 167) n (%)
No information provided	78 (57,4)
Maps-direction	30 (22,1)
Restaurant location - Menus	35 (25,9)
Taxi numbers	38 (27,9)
Public transit schedule / route	21 (15,4)
Directions for nearby stores	33 (24,3)
Other	21 (21,6)

About half of respondents did not receive any helpful information where they stayed, while others received various types of practical information.

Table 14: How much of the information was in English?

	(n= 167) n (%)
None in English	15 (23,4)
A bit	7 (10,9)
About half	22 (34,4)
Quite a lot	8 (12,5)
All in English	12 (18,8)

Of this information, almost one-quarter was not in English, with just over 18% entirely in English. This points to a lack of consistency in available information.

Costs incurred while out-of-region

As mentioned above (in “Strategies for communicating”), there are several different kinds of costs, including the patient’s own expenses for travel, food and lodging (if they are an out-patient) as well as expenses for a support person, if they have one. Refunds are available for a portion of the expenses, however the remaining amounts can create a financial burden. During focus group discussions, participants observed that some families simply cannot afford it, so in some small communities, people create a Facebook page and neighbours drop off donations at the store to help out with the cost. In other communities there may be a foundation or the community may raise money to help people travelling for health services. Overall, there seems to be a broad range of experiences with and knowledge of refund possibilities, leaving some people out in the cold. There also seems to be confusion, or conflicting information, about what exactly is refunded, depending whether or not a person is an outpatient, the length of stay, the type of expense, whether the patient is considered to need accompaniment or not, and more.

Table 15: What costs were refunded for the out-of-region stay?

	(n= 167) n (%)
I did not know refunds were available	19 (11,6)
No costs were refunded	17 (10,4)
A portion of the costs were refunded	94 (57,3)
All costs were refunded	26 (15,9)
Other	8 (4,9)

While refunds are available for a portion of the expenses, not all people know they are (11.6%) and about 10% of respondents said that no costs were refunded.

For those who did know that refunds were available, that information came mainly from a member of the hospital staff (60%) or a family member or friend (24%). In some cases, the required forms were filled out by health care staff (transport office for example).

One survey respondent commented on what could have made their experience better: “I couldn’t find any fault with what happened in that operation, with the exception of having to pay for medical transport on my way home. It didn’t greatly affect me, but for those with limited income, it must be awful. I felt horrible after my operation, and knew that the long bus ride would be worse due to worrying about my post-surgery state.”

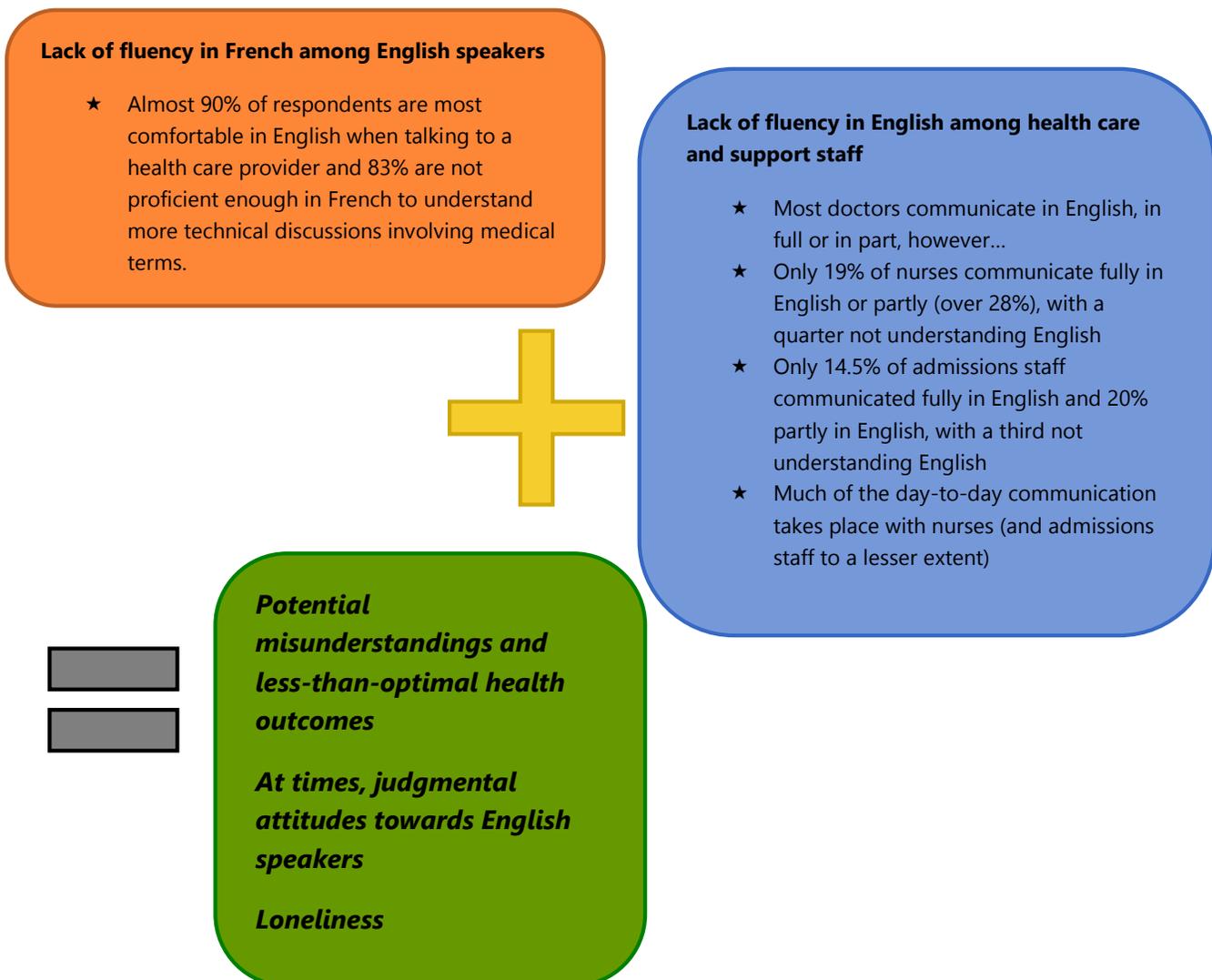
In the next section we will identify the main challenges and the actions that could be undertaken to address them.

DISCUSSION

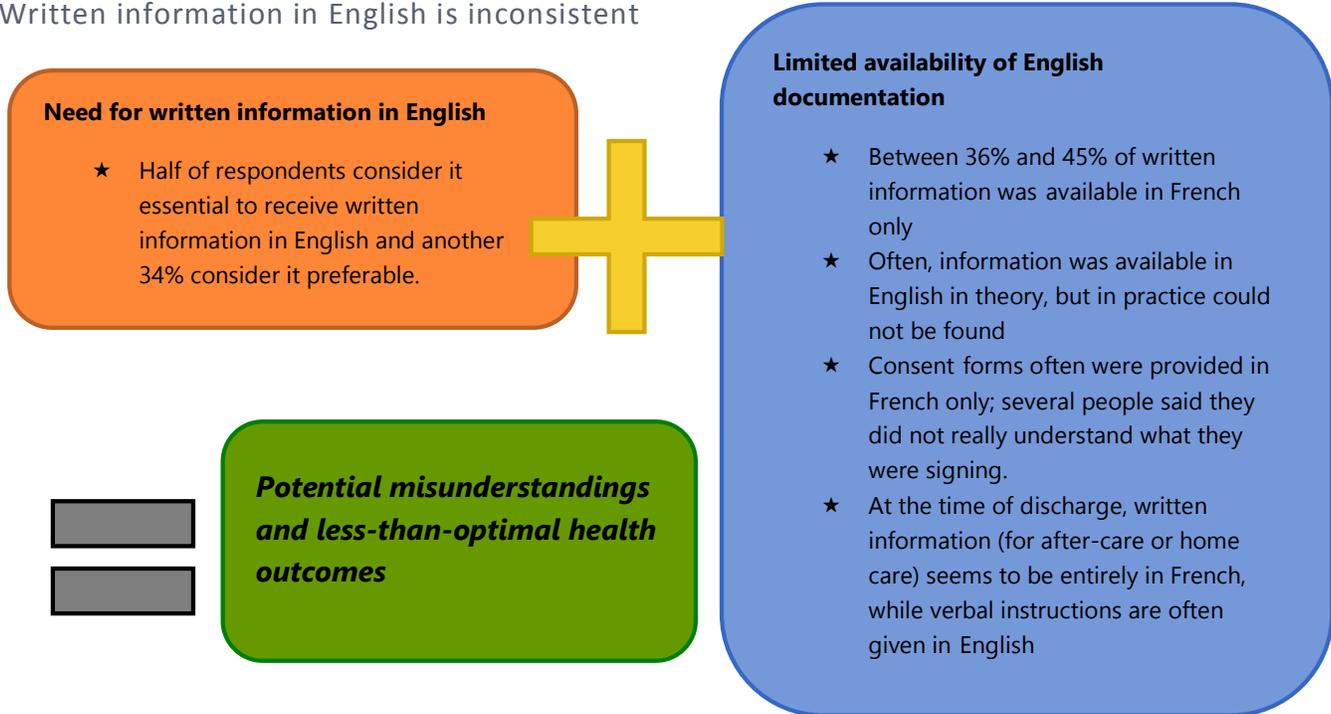
Main challenges

Based on the information we have compiled from the survey, as well as complementary information from focus groups, the main challenges facing English speakers when they travel to Quebec City are as follows.

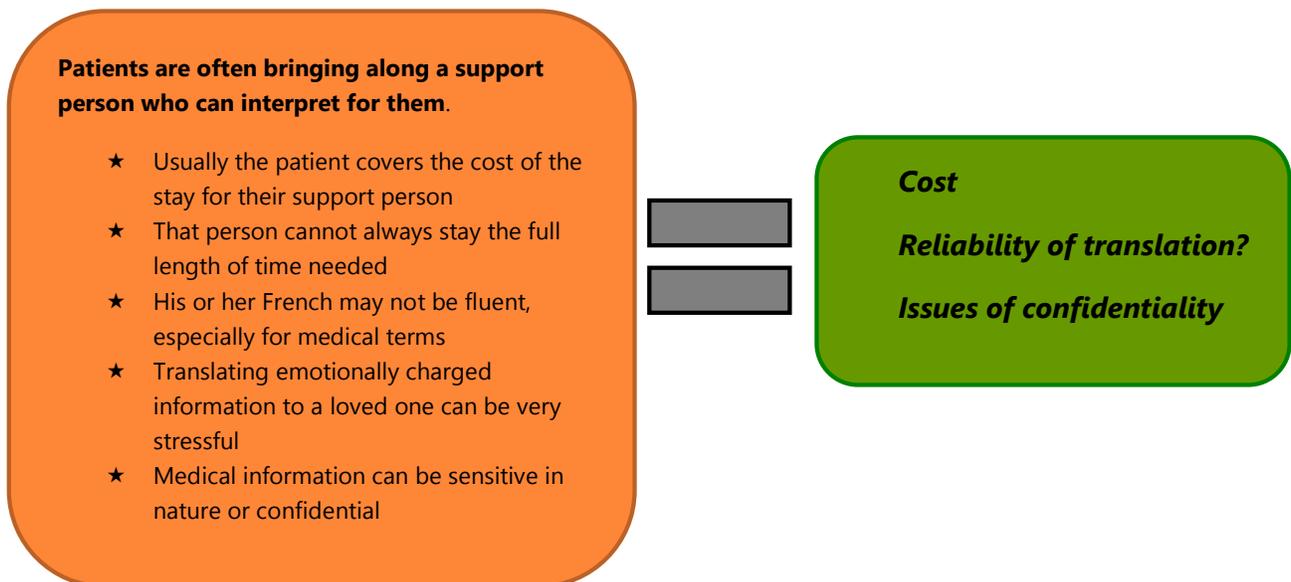
Language barriers in communicating with health care staff



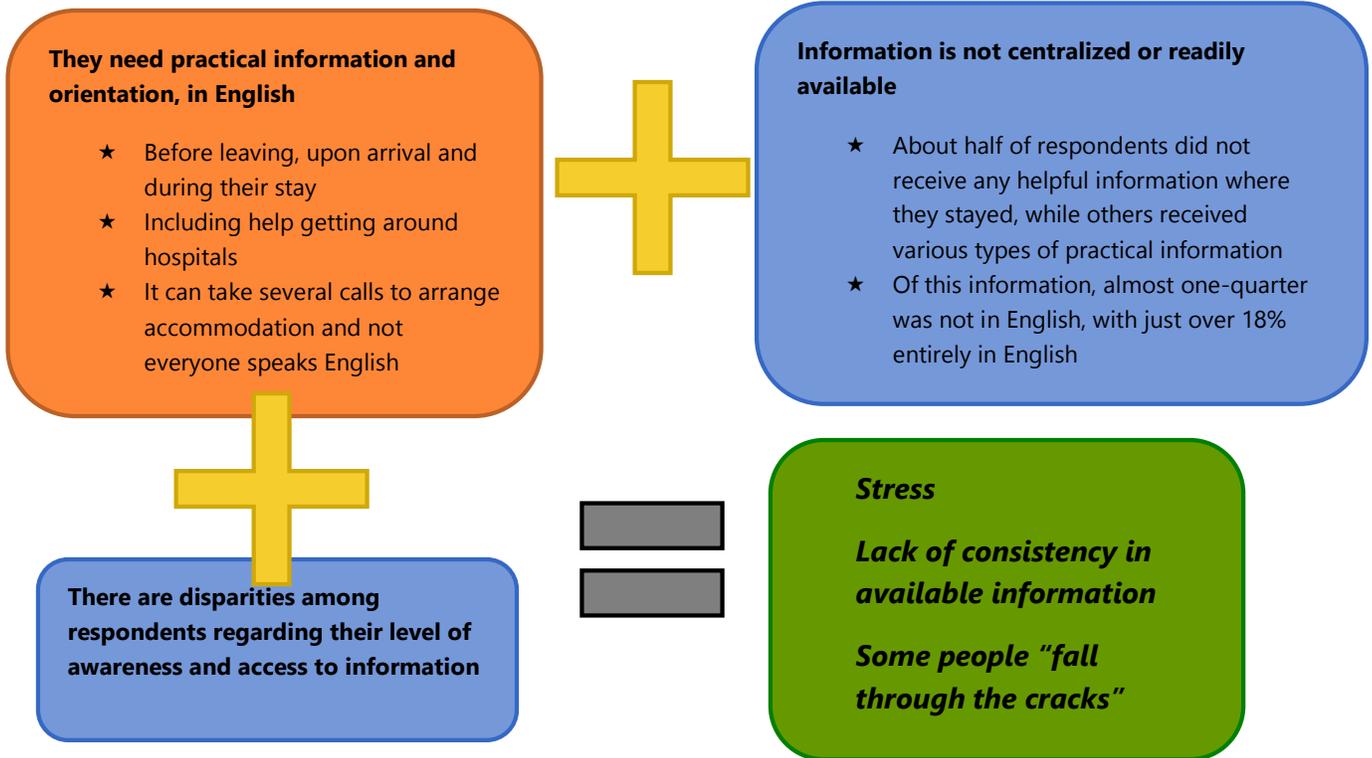
Written information in English is inconsistent



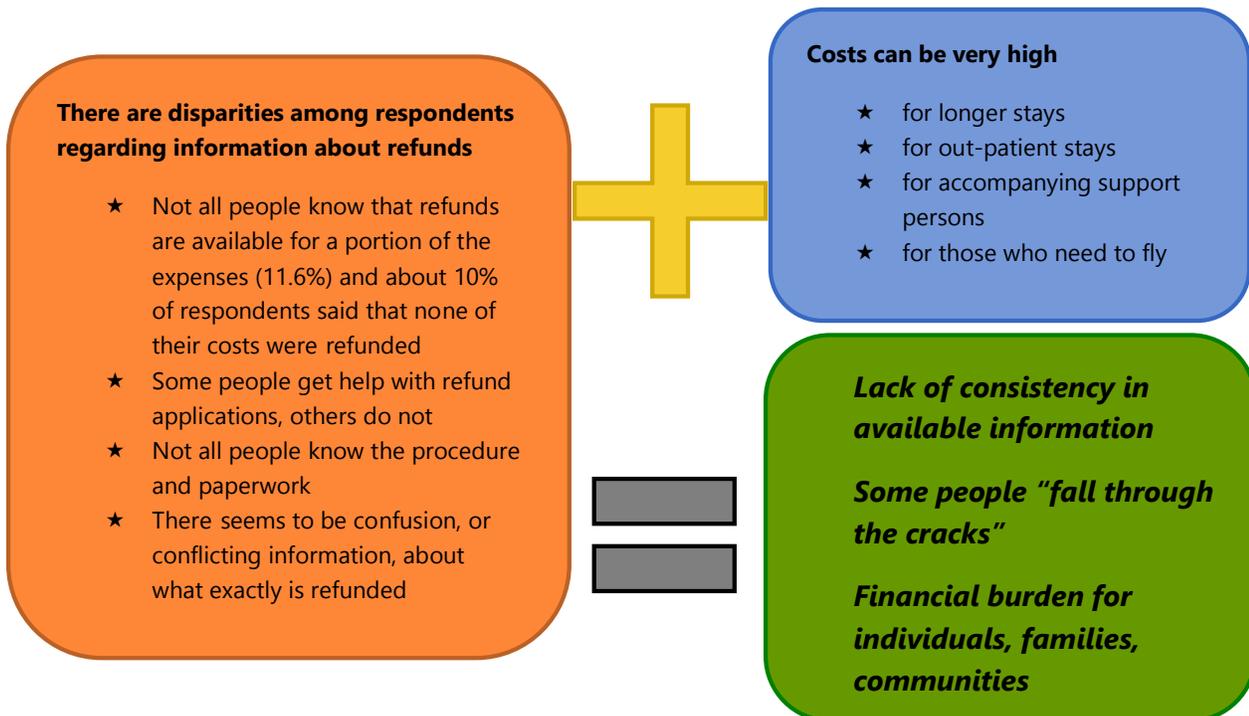
Interpretation is often being provided by relatives or friends



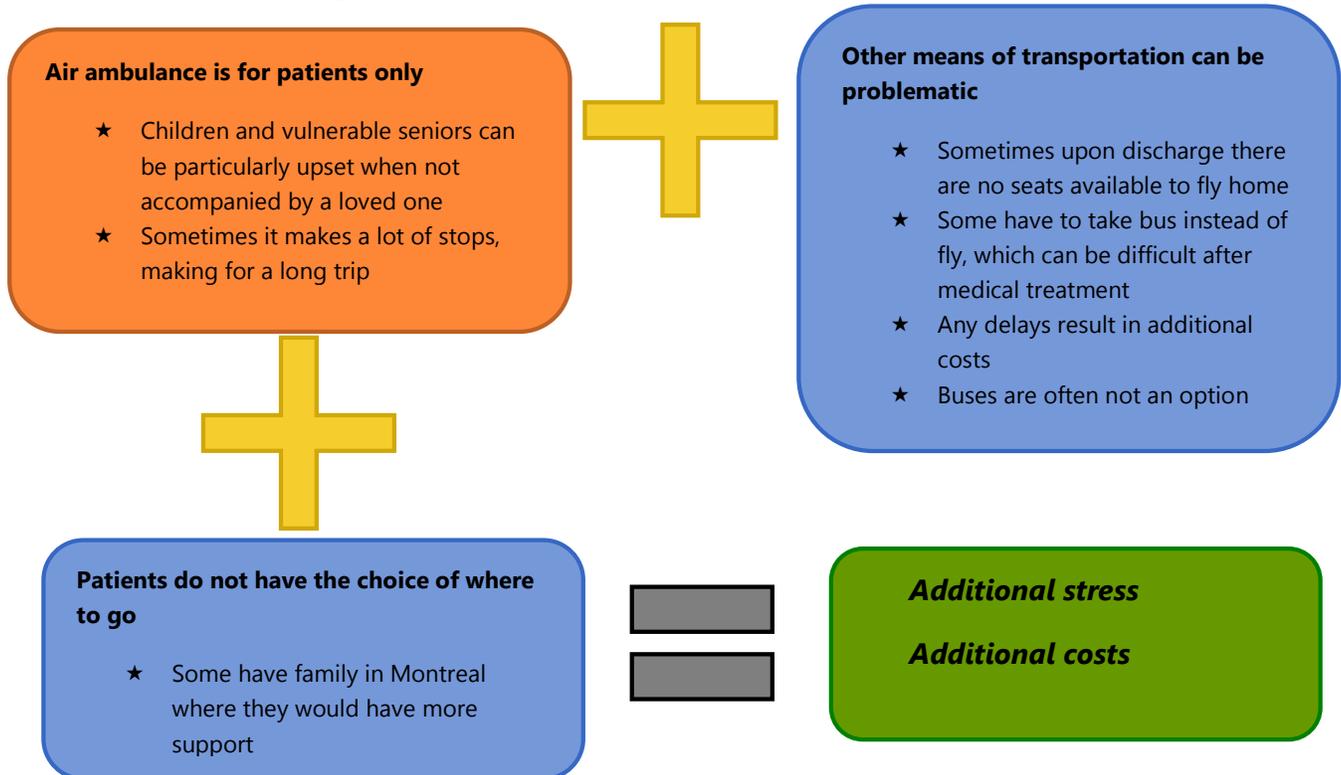
Persons travelling from eastern regions are unfamiliar with Quebec City and its hospitals



Costs can be significant for people who need services out of their region



Transfer protocols can generate additional stress



Not just a question of language

Many of these challenges are not just a question of language. Any patient travelling from outside the region could experience some of these difficulties. This study has helped to shed light on a broad range of issues, some of which affect English speakers more specifically and some of which affect all inter-regional patients. In our view, this is a strength, since some of the solutions have the potential to improve the experience for the population as a whole, while also improving the situation for the linguistic minority.

Areas to consider for future actions and possible solutions

Many suggestions were provided by survey respondents and focus group participants regarding ways to make the experience of travelling outside their region of residence easier.

Provide written information and documentation in English

The idea would be to develop an information packet for which would be:

- centralized
- on-line

- printable for hard copies
- updated, as needed
- divided into modules, by theme and by region, so that information is user-specific

This would require collaboration among regional associations, health care institutions and other public agencies. There could be two types of information.

INFORMATION TO BETTER PREPARE PATIENTS PRE-TRANSFER

Existing documentation would need to be identified and could include:

- information to prepare to leave (what to bring, who to contact, etc.)
- refund information (forms, policies, etc.)
- available financial support
- maps of the hospitals
- lists of places to stay, by neighbourhood and cost
- maps of the city
- volunteer support networks

Effort required?

This seems quite realistic in a 6-month time frame. CASA could oversee the work, to be completed by their project coordinator, in collaboration with the other regional associations. CHSSN could provide logistical and technical support, based on the health passport it developed.

HEALTH-RELATED DOCUMENTATION IN ENGLISH

The approach would be to begin with one hospital (Hôpital Laval?) and develop a process for creating this. It would require collaboration and existing documentation would need to be identified. This could include:

- information about procedures, treatments, after-care, etc.
- consent forms
- etc.

Effort required?

This would likely take longer and be more labour-intensive, but given a high level of interest and collaboration on the part of health care establishments, we think it could be done.

Develop a support network for patients

Many respondents said that it would be very helpful if they had someone to help them while away from home, as a contact person. Assistance might include:

- meeting them upon arrival and helping them to find their way around, either at the airport or bus station, or at the hospital
- answering questions
- helping find accommodation, places to eat, etc.
- visiting and providing moral support
- helping to provide translation (but perhaps not themselves offering translation)

Effort required?

This would likely take a significant amount of time and coordination. A new network would probably have to be set up, but could use an existing group as a starting point. This looks like a more long-term project, but one that JHCP is in a good position to do. Certain models exist (see Les Accompagnantes de Québec) where volunteers are trained, can be available as suits their situation, and can be compensated for their availability; users make a voluntary contribution according to their ability to pay; and some public and private funding is provided.

Facilitate communications between ES patients and health professionals

Various initiatives are underway to achieve this objective (McGill training and retention project, regional initiatives such as Mellow Yellow, etc.) Work is also being done to examine the possibility of providing professional interpreters. This is an area to continue exploring, perhaps to begin with, in dialogue with the hospital chosen for a pilot project.

Policy changes

There are certain policy changes that could help to improve the situation, such as:

- Refunds for support persons
- More complete refunds for longer stays
- Air ambulance for children

Effort required?

This is a long-term, highly political action, with a high level of uncertainty, but part of the on-going work of various organizations, including the CHSSN.

CONCLUSION

In conclusion, many of the people living in Quebec's eastern regions may have to travel out of their region of residence for specialized health care services at some point in their life, for themselves or to accompany someone close to them. Among the respondents to our survey and the participants

in the focus groups discussions we held, many of these people are older, do not have a level of proficiency in French that would enable them to receive medical services entirely in French, and therefore prefer to communicate in English when it comes to health care. On the other hand, health care staff do not all speak English fluently, and this seems to be the case particularly with admissions/reception staff and many nurses, who interact most with patients (doctors are more likely to be comfortable communicating in English). Written information is not always available in English, yet it can sometimes help to compensate for a lack of spoken English. These combined issues can result in less-than-optimal health outcomes as well as a sense of loneliness or isolation among those least able to communicate in French.

As a way to make their situation easier, the participants in this study reported that many English speakers bring along a support person when they are transferred out of region, usually someone who speaks French fluently (or better than they do), often at their own expense. Although the linguistic, moral and physical support is undoubtedly very comforting, it does raise the issue of the reliability of the translation, the confidentiality of medical information, and the cost borne by individuals, families and communities, particularly when stays are long and people need to travel by air.

Many residents of the eastern regions are not very well-acquainted with Quebec City and can feel disoriented, intimidated and stressed when arriving in what is a fairly large city under already stressful conditions, as they are dealing with a health problem. Practical information in English is not always easy to find and there seems to be disparities among respondents regarding their level of awareness and access to information.

Likewise, information concerning refunds for their expenses also seems to be inconsistent, with some people receiving financial assistance and refunds while others do not. Also, some types of expenses are not covered and, depending on the situation, can amount to significant costs.

Finally, transfer protocols can generate additional stress (and costs sometimes), most obvious in the case of young children or elderly patients who take an air ambulance without a familiar face.

We have identified several possibilities for taking action to address these challenges. Others may also be identified as we continue to explore ideas with partners. The most feasible idea in a shorter time-frame is putting together an information packet with a range of information organized into modules and available on-line. Some would concern practical information about Quebec City and its health care establishments, as well as refunds, preparing to leave home, making arrangements and resources available. The information could be different depending on the region of origin, the health care establishment they are going to and the stay planned (long or short term, in-patient or out-patient, with support person or not, etc.).

We would also like to do a pilot project with one of the hospitals to jointly develop a variety of approaches to improve communications with English-speaking patients, including written information. In order to identify a hospital with which Jeffery Hale Community Partners could begin working to address some of these challenges, we assessed where most patients are transferred and for what sorts of health conditions: Hôpital Laval was the most frequented and cardiology was the most common health problem for which patients were transferred to Quebec City. This would be the most obvious choice. Certain policy changes could also be brought to the attention of the relevant government departments.

In all cases, we favour a collaborative approach where solutions are found in dialogue with those most involved and in a way that will benefit the greatest number of health care users. This project also has the potential to be extended to other regions and could therefore be an opportunity for developing tools, collaborative approaches and solutions that involve a broad range of partners (community, government, volunteer academic) which could then be adapted elsewhere.