

INTER-REGIONAL ACCESS TO SPECIALIZED HEALTH AND SOCIAL SERVICES

*for English-Speakers from
Eastern Quebec*

November, 2015

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Acknowledgements

This project was a collaboration between the Centre intégré de santé et des services sociaux de la Gaspésie (managed by the Committee for Anglophone Social Action—CASA) and Jeffery Hale Community Partners (JHCP)



in collaboration with the following community organizations:



Research support was provided by Mary Richardson, PhD & Hélène Gagnon, PhD.

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<i>Main issues</i>
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The study

A community-led study

Study design

*A collaboration among
community organizations*

Data collection

A community-led study

The project objectives are :

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

The concern

Residents of rural and remote regions in eastern Quebec have to travel to urban centres to receive certain specialized health care, most often to Quebec City, Montreal or a smaller city such as Rimouski.

Travelling to a city for health care treatments can be a costly, stressful and lonely experience for many people, particularly if they do not speak fluent French.

The project

Two community-based organizations serving English-speaking communities in Quebec led a study to better understand the experience of English speakers from the eastern regions of Quebec who have to travel to larger urban centres for specialized health and social services.

The specific challenges facing English speakers were known only anecdotally, but needed to be better understood before effective action could be taken to address the needs of this population.

Five other community-based organizations, in collaboration with their regional partners in health and social services, will be involved in identifying and implementing actions to address the issues and support their English-speaking communities.

Study design

Participatory action research

The approach being taken for this project 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.

Led by community organizations

With funding from Health Canada, provided through the Community Health and Social Services Network (CHSSN), for adapting services to the needs of official language minority groups.

Supported by researchers

Mary Richardson, PhD and H el ene Gagnon, PhD



A collaboration among community organizations

Eastern regions + Quebec City

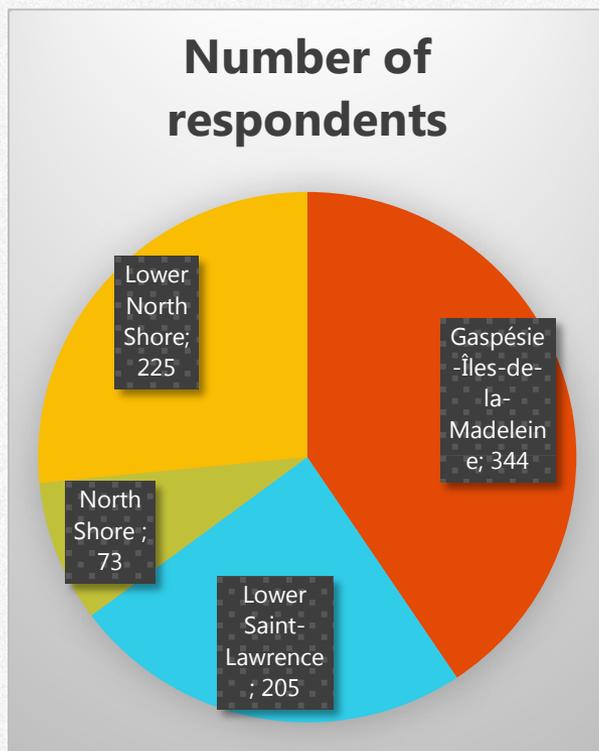
Quebec City receives the largest proportion of patients travelling from these regions. JHCP is engaged to work on developing actions in Quebec City to help meet the needs identified.



North Shore
Community
Association



Data collection



Survey data

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 a representative sample of English speakers.

A total of 847 surveys were filled out between November 2014 and April 2015.

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

Interview data

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.

A total of 13 focus group discussions were held with a total of 85 community members.

They were held in public spaces such as a school, a community organization office, a community centre or other.

The information gathered through these discussions is extremely helpful in understanding the experience of those who have travelled outside their region to receive specialized services, whether for themselves or with a loved one.

This is where we can better understand the social, financial and emotional challenges faced by these community members.

Study participants

Survey respondents

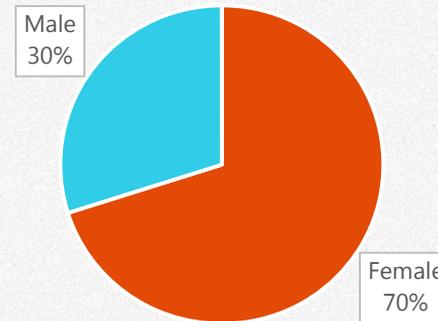
*Proficiency speaking
French*

Proficiency reading French

Survey respondents

Socio-demographic characteristics

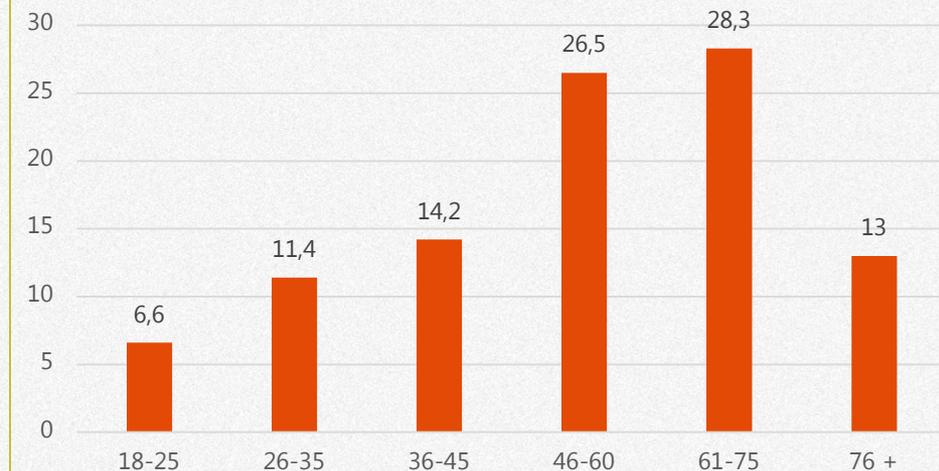
Sex of survey respondents



70% of survey respondents are women and 30% are men.

About 41% of respondents are 61 years of age or older, and another 41% are between 36-60.

Age groups of survey respondents



Proficiency speaking French

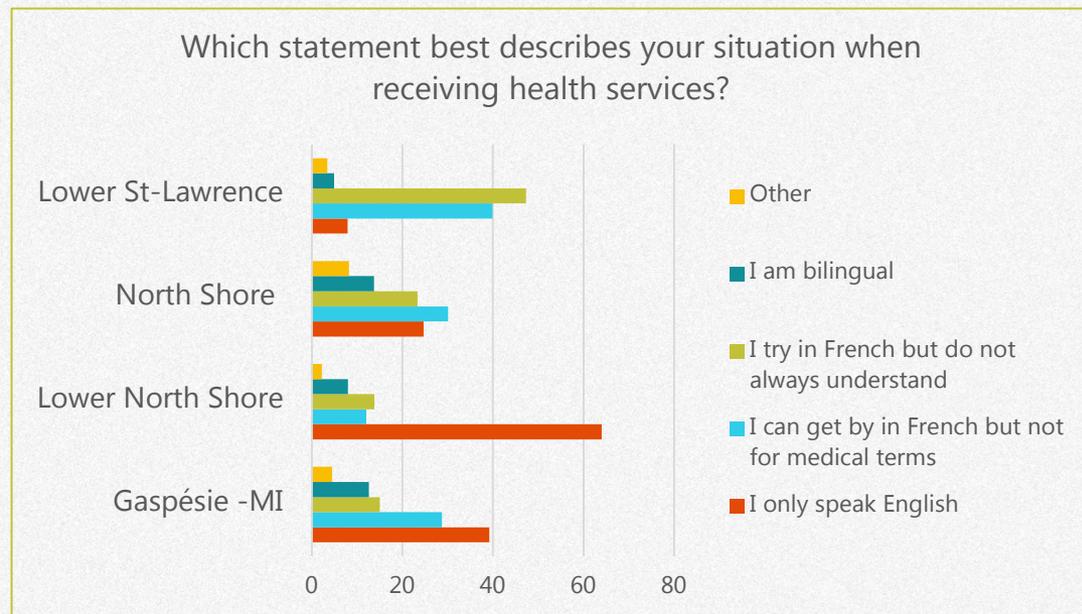
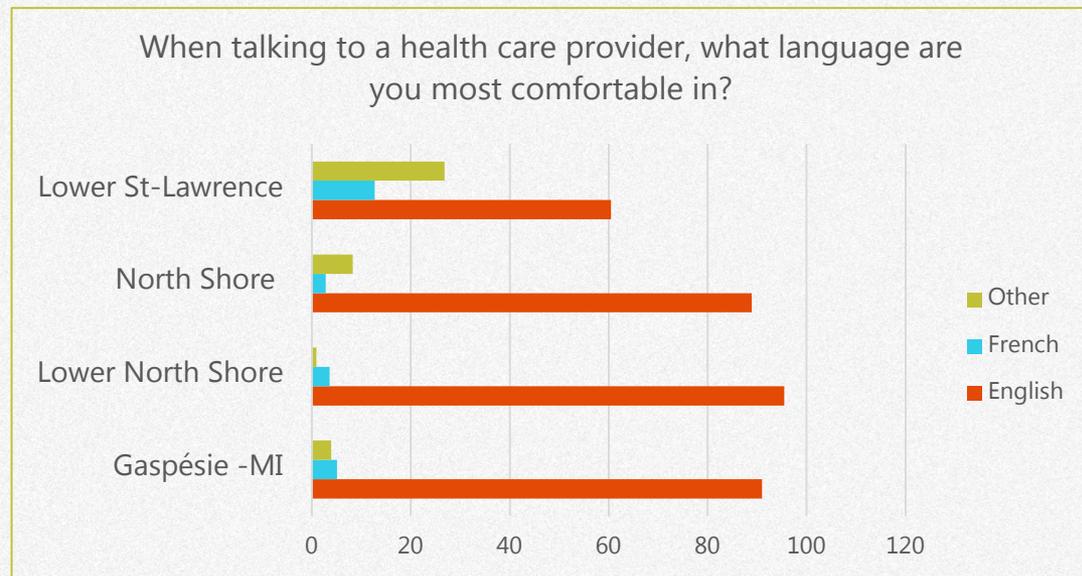
Overall, more than 75% are not proficient enough in French to understand more technical discussions involving medical terms.

The vast majority of English-speakers are most comfortable talking to a health care provider in English.

The rates are slightly lower in the Lower Saint-Lawrence, where a higher percentage of respondents are comfortable in both languages.

Particularly on the Lower North Shore and in the Gaspé-Magdalen Islands, many people can only speak English.

Many respondents said they try to speak in French, but do not always understand what is being said; or they can get by in French in other situations, but have difficulty with medical terms.

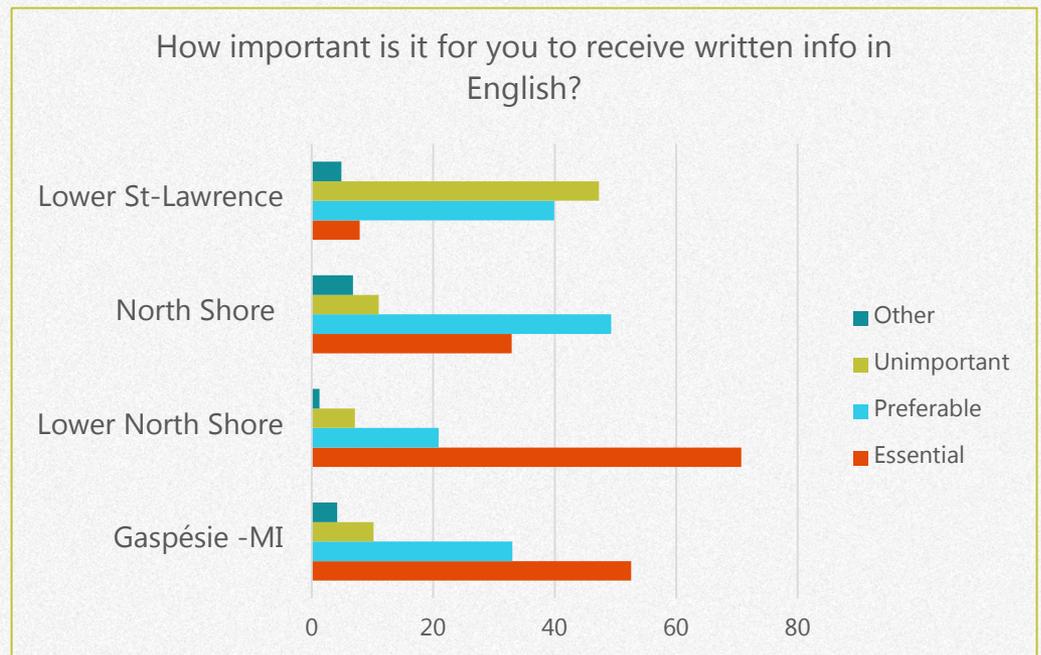


Proficiency reading French

Overall, almost half of respondents consider it essential to receive written information in English and another 33% consider it preferable

On the Lower North Shore and in the Gaspé-Magdalen Islands, rates are even higher.

In the Lower Saint-Lawrence, proficiency in both languages is much higher.



Services out-of- region

Cities where services were received

Specialized services received

Hospitals in Quebec City

Interactions with staff while out-of-region

Variations between regions in the use of English

Written information provided while out-of-region

Cities where services were received

Hospitals

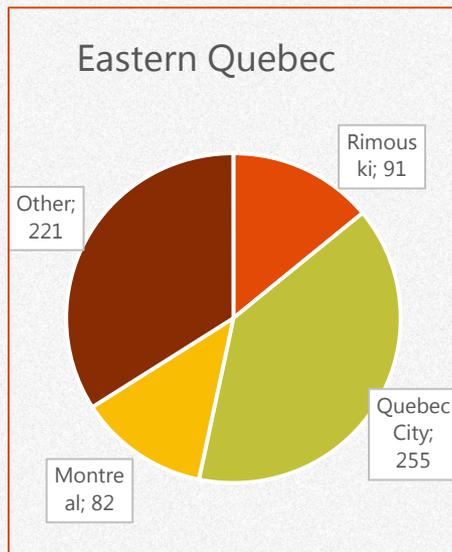
15% had been to Rimouski: these are mostly Gaspesians

11% had been to CHUL (QC)

10% had been to Hôpital Laval (QC)

Half of respondents replied « other »

This was mostly people from the Lower North Shore who have travelled to Sept-Îles (46%) or Blanc-Sablon (27%).



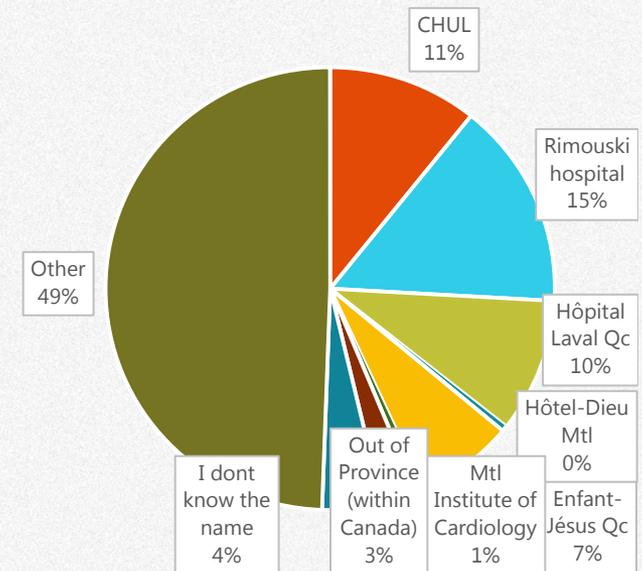
Cities

Overall, the largest number of respondents had travelled to Quebec City.

The second largest number replied « other »

Most of the respondents who replied « other » were from the Lower North Shore and had travelled to Sept-Îles, Blanc-Sablon or Newfoundland.

16% had travelled to Montreal and 17% had travelled to Rimouski.



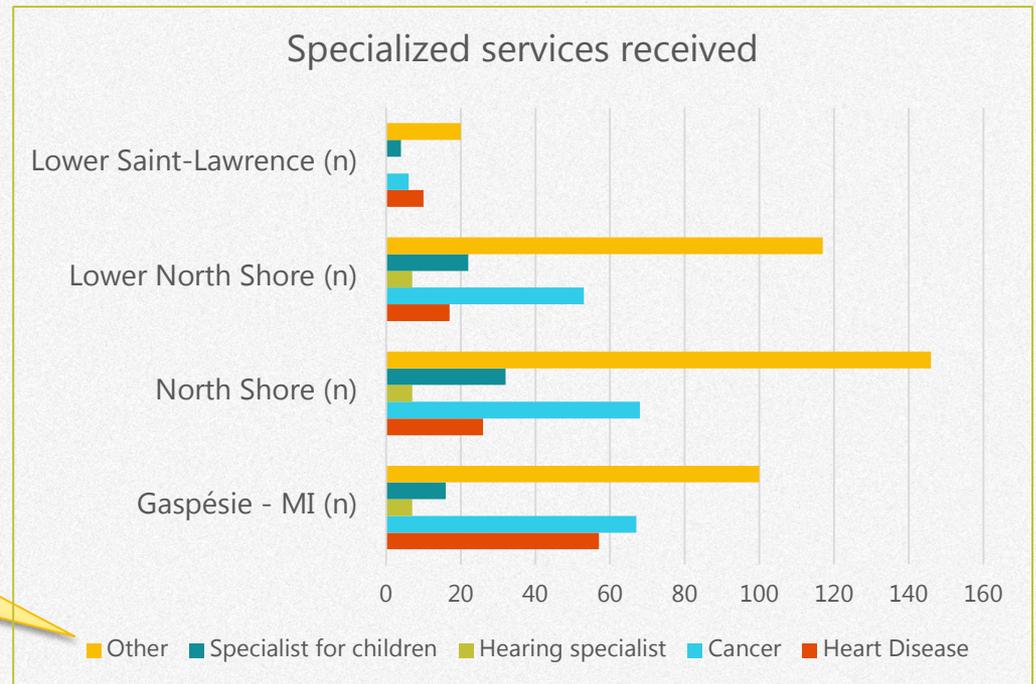
Specialized services received

Overall, the most common reasons for transfer were cancer treatments and cardiology

- 27.7% oncology (cancer)
- 18.3% cardiology (heart disease)
- 10.2% pediatrics (for children)
- 55% replied « other »

Among the 167 respondents who had travelled to Quebec City for health care, the rates were slightly different.

- 32.5% cardiology
- 22.9% oncology (cancer)
- 12% pediatrics



Almost half of respondents answered "other" to this question. See next page.

Hospitals in Quebec City

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

Overall, Hôpital Laval is the most frequented hospital, followed by CHUL, Hôtel Dieu and Enfant-Jésus.

The type of health care received in Quebec City was first of all cardiology, followed by cancer treatment, pediatrics and orthopedics.

Hospital or center where services were received	(n= 167)
Hôpital Laval	41 (24.7%)
CHUL	37 (22.3%)
Enfant Jésus	30 (18.1%)
Other*	51 (30.7%)
Hôtel-Dieu-de-Québec	30
Saint-Sacrement	12
Saint-François-d'Assise	9
I don't know	7 (4.2%)

Type of health care	(n= 167)
Heart Disease	54 (32.5%)
Cancer	38 (22.9%)
Specialist for children	20 (12%)
Hearing specialist	2 (1.2%)
Other*	66 (46.2%)
Orthopedics	16
Neurology	6
Ophthalmology	5
Cardio-pulmonary	5
Gastro-intestinal	4
Kidney disease	3
Endocrinology	2
Perinatal care	2

Interactions with staff while out-of-region

"I find in my experience so far, most health care workers are friendly. My husband does all of the communicating for me as he is bilingual. I would not be comfortable on my own as I speak very little French."

"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"

Both patients and health care staff develop strategies for communicating with each other. What is most important is a positive, receptive attitude.

Survey questions concerned two forms of communication: verbal communications with health care staff and written communications. Many patients (and those accompanying them) also develop alternative strategies for dealing with communications issues. In focus group discussions with residents of the Gaspésie-Îles-de-la-Madeleine region, several points were made.

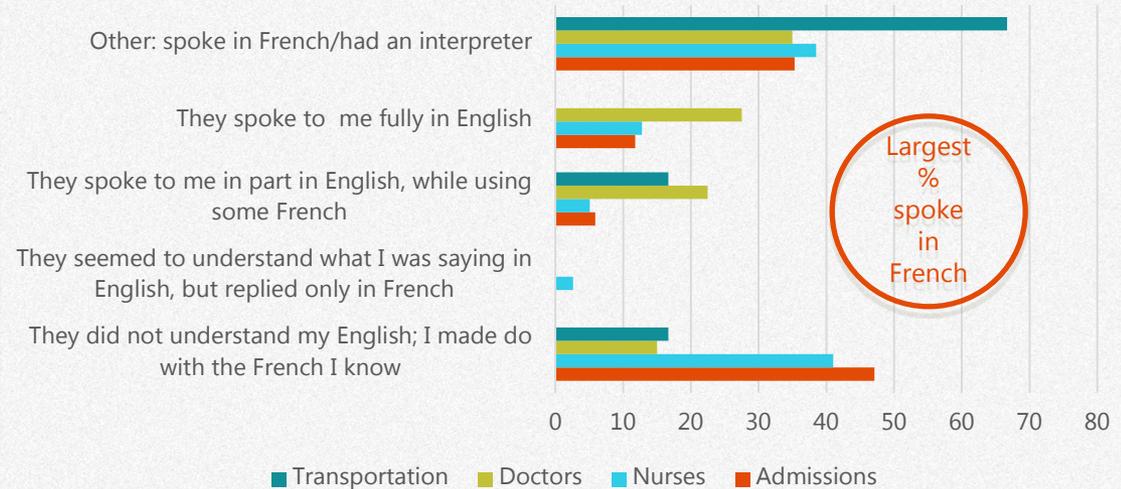
- 1. The greatest communications challenges were faced at reception and with nursing staff.**
- 2. There are great disparities in the levels of bilingualism among health care staff and the situation has changed over the years.**
- 3. Some of the stress or a feeling of inferiority is experienced when 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.

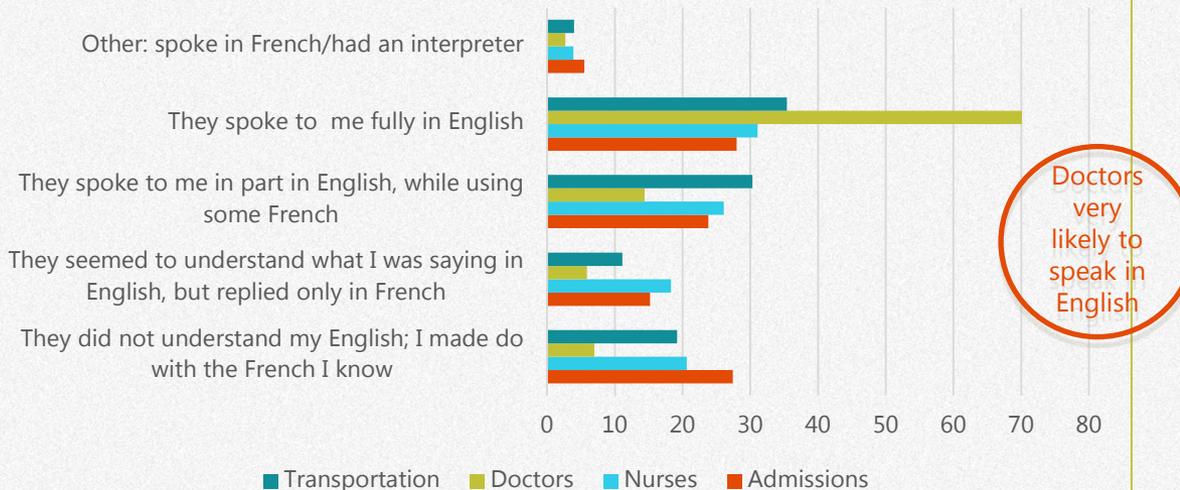
Several people had experienced negative attitudes and some were even told "you live in Quebec, you should speak English" or "I do not have to speak English". In some cases, staff would try to do their best, and one person said they apologized for not speaking English.

Variations between regions in the use of English

Lower Saint-Lawrence

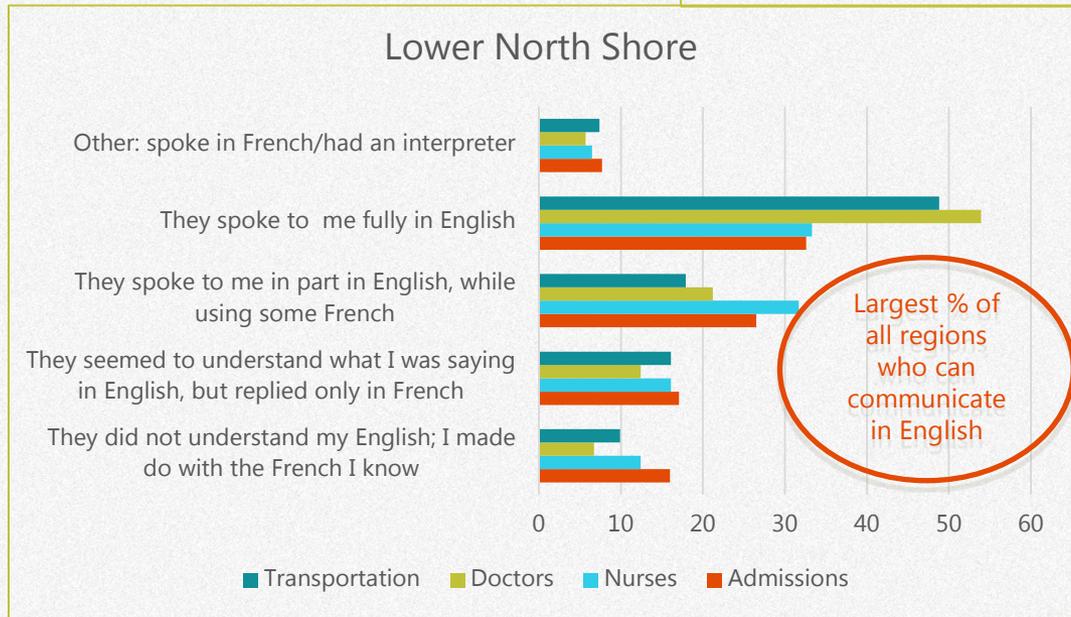
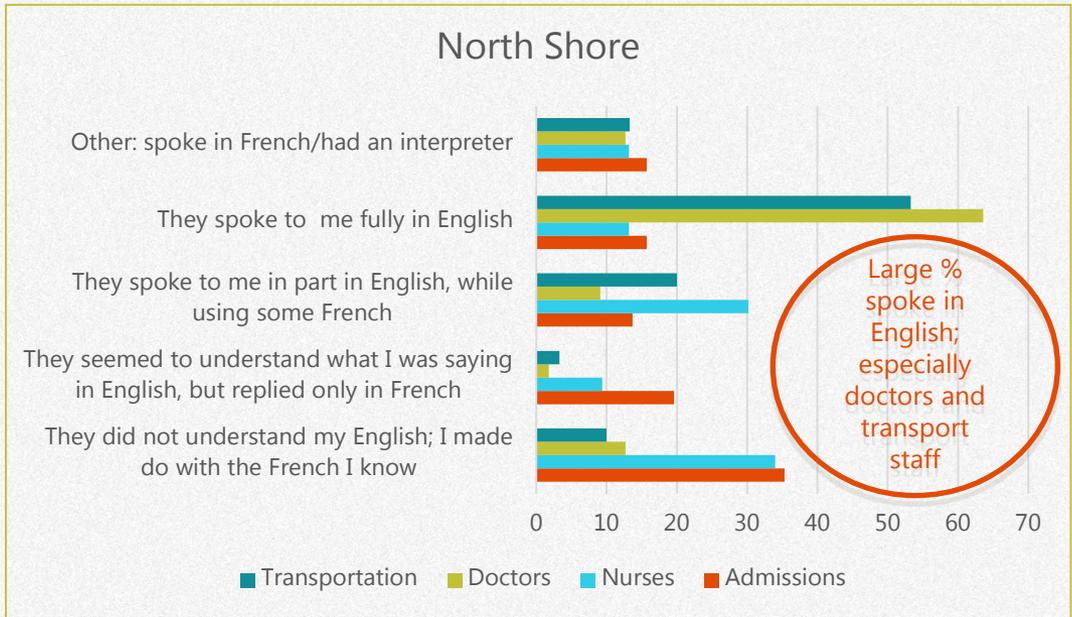


Gaspésie-Îles



"My French is very good, but it would be nice to have more in my mother tongue."

Variations between regions in the use of English



"All English service would be better, but we have to try as well!!! I noticed during all my trips to the outside hospitals in the past two years that if I made an effort to speak French that most people would make an effort to speak English. I feel that more effort was made in Quebec than in Sept Iles. I really feel bad for those patients that absolutely cannot manage in French. I think that they would encounter problems for sure. This can be very problematic because important information can be misunderstood and more stress is put on the patient."

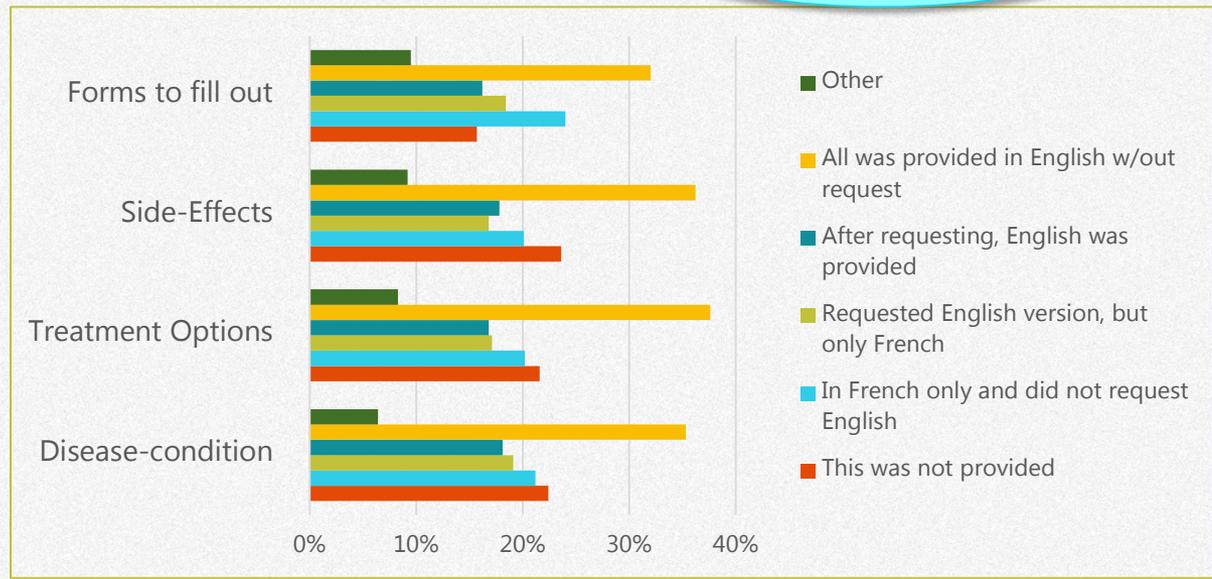
Written information provided while out-of-region

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.

↑ I buy seeds for the vegetable garden and the package is in 5 languages. Health should be far more important. A simple pamphlet on how to wash your hands is not available in English ..."

In the focus group discussions, participants said 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; several people said they did not really understand what they were signing.

Staying out-of-region

Length of stay out-of-region

Accommodations out-of-region

Refunds for costs

Preparing to go home

Length of stay out-of-region

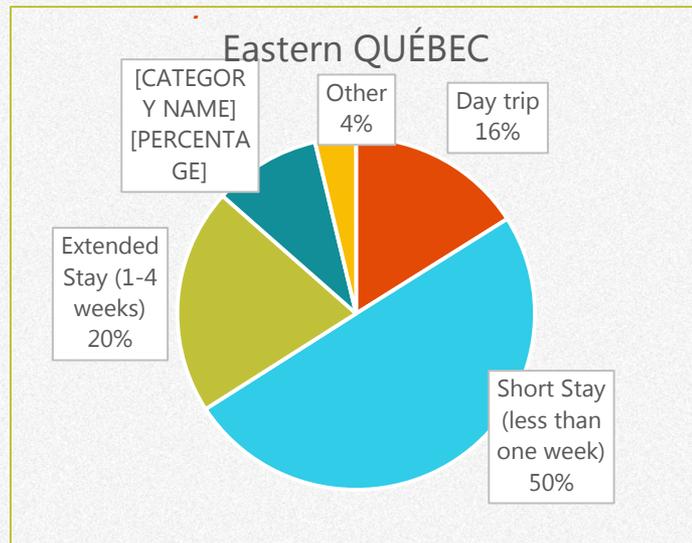
Most stays were less than one week, with another 20% lasting between a week and a month.

Extended stays were most common among residents of the Gaspésie-Magdalen Islands, while day trips were most common among residents of the Lower Saint-Lawrence.

This information is important in understanding the challenges facing people from out of the region, since it has repercussions on many levels

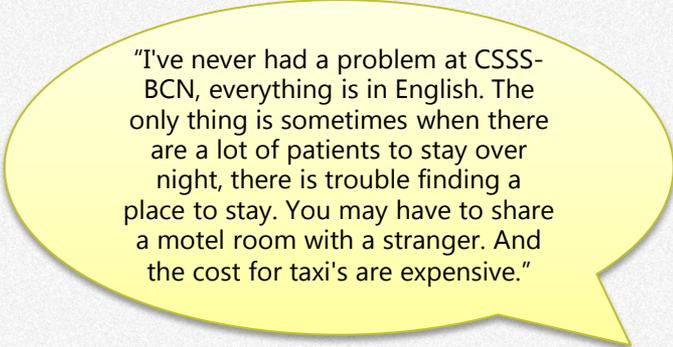
Longer stays can:

1. pose a significant financial burden on individuals, families and communities
2. result in people being alone while dealing with the stress of an illness (since caregivers are not always able to stay for a long time), and
3. mean that the stress of all the various challenges is experienced for some time.



"The time was very lonely not having anyone to speak to in English. My family would take turns to come to Quebec to visit me but their time was very limited because of how costly it was for the hotels and food etc..."

Accommodations out-of-region



"I've never had a problem at CSSS-BCN, everything is in English. The only thing is sometimes when there are a lot of patients to stay over night, there is trouble finding a place to stay. You may have to share a motel room with a stranger. And the cost for taxi's are expensive."

Accommodations

Slightly more than one-third of respondents stayed in a hotel or motel.

People from the Lower Saint-Lawrence were more likely to stay with family members.

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.

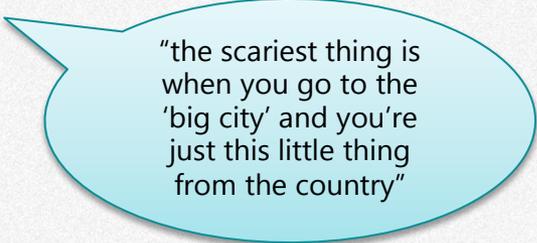
Access to helpful information

Half of respondents said that they had not received 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.

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



"the scariest thing is when you go to the 'big city' and you're just this little thing from the country"

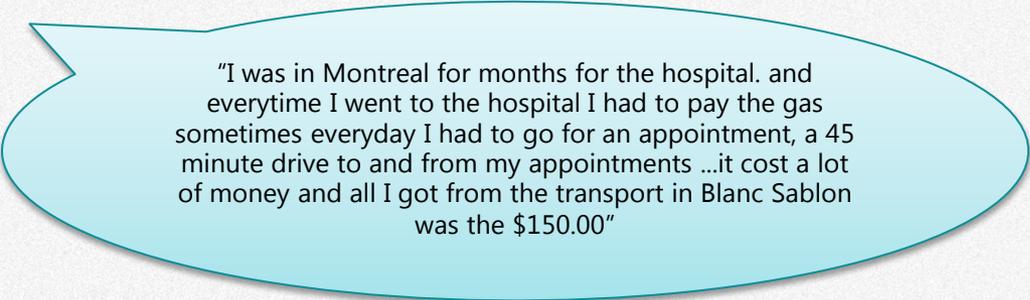
Refunds for costs

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.



"I was in Montreal for months for the hospital. and everytime I went to the hospital I had to pay the gas sometimes everyday I had to go for an appointment, a 45 minute drive to and from my appointments ...it cost a lot of money and all I got from the transport in Blanc Sablon was the \$150.00"

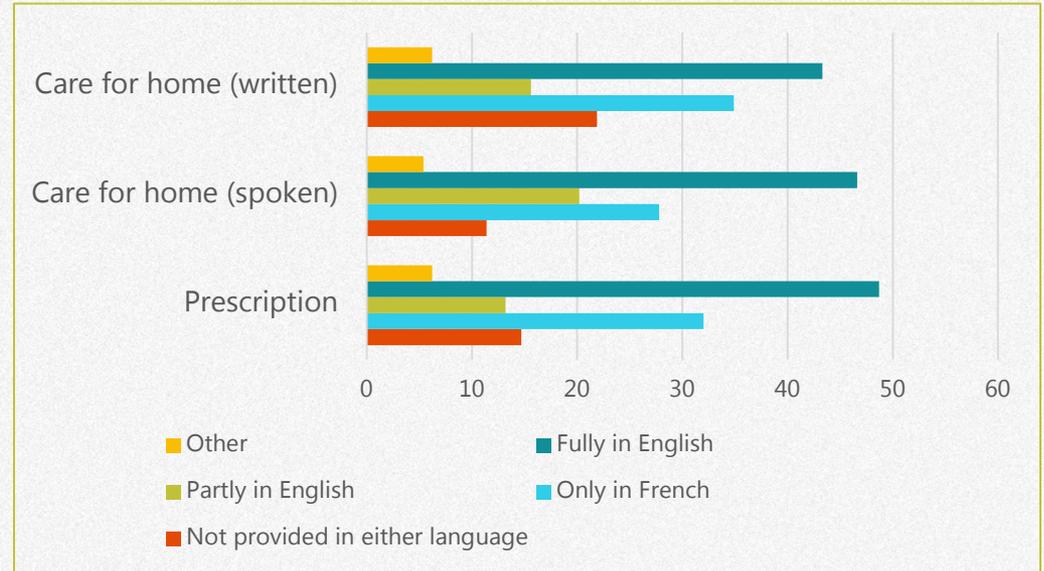
Preparing to go home

Before returning home following medical treatments, patients often receive instructions about follow-up care. These instructions may be provided in writing or verbally and may also include prescriptions for medication.

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.

This can be a very important factor in ensuring good recovery and health outcomes.

“It is very difficult for an English senior to navigate the health institutions in Quebec and Sept Îles and in my point of view very dangerous to not provide pre and post surgery information in [English].”



Main issues

Issue 1: Language barriers

*Issue 2: Written
information*

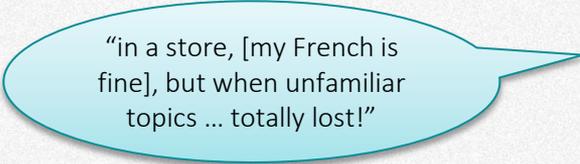
Issue 3: Interpretation

*Issue 4: Unfamiliarity with
city and hospitals*

Issue 5: Costs

Issue 6: Transfer protocols

Issue 1: Language barriers



“in a store, [my French is fine], but when unfamiliar topics ... totally lost!”

Existing strategies

Mellow Yellow

In the GIM, health care staff can choose to have a yellow band on their ID, letting patients know they can speak English.

McGill second language training

Health care personnel can take English-language training.

Lunch-time conversations

In Gaspé, staff can chat in English during lunch-time.

There are language barriers between patients and health care staff.

English speakers in eastern Quebec are not all fluent in French, especially when it comes to receiving health care services.

Almost 85% of respondents are most comfortable in English when talking to a health care provider.

These rates are above 90% in the Gaspésie-Magdalen Islands region, as well as on the North Shore. In the Lower Saint-Lawrence they are only 60%, with a much higher proportion of English speakers being fluent in French.

In Eastern Quebec: a total of 75% of respondents are not proficient enough in French to understand more technical discussions involving medical terms.

This is particularly problematic for vulnerable populations such as seniors with decreasing autonomy.

On the other hand, health care and support staff are not all fluent in English.

Many doctors communicate with their patients in English (in full or in part) while nurses often speak partly in English or understand it. Admissions staff are slightly less likely to be able to communicate in English.

The potential consequences of this language barrier include misunderstandings, miscommunication and less-than-optimal health outcomes as well as a feeling of loneliness during longer stays. Also, some caregivers seem to have judgmental attitudes towards English-speaking patients.

Issue 2: Written information

Existing strategies

Partnerships with regional English-language organizations can help with translations

Written information in English is inconsistent

Almost half of respondents (44.8%) consider it essential to receive written information in English and another 32.9% consider it preferable.

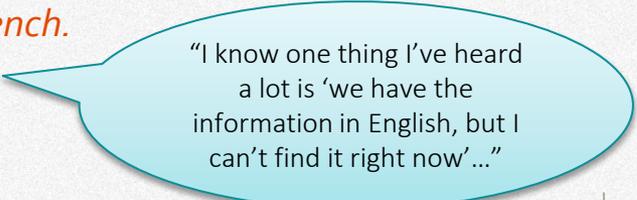
This includes information on diseases and conditions, treatment options, side effects and consent forms.

In all cases, a little over one-third of respondents said they received information in French, while about two-thirds received information in English.

Sometimes written information is available in English in theory, but in practice could not be found. Most worrisome, consent forms sometimes 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) was in French in about one-third of cases, while verbal instructions were more likely to be given in English.

The potential consequences when written information is not available in English include misunderstandings, miscommunication and less-than-optimal health outcomes for those unable to read and fully understand written information on health issues in French.



“I know one thing I’ve heard a lot is ‘we have the information in English, but I can’t find it right now’...”

Issue 3: Interpretation

Existing strategies

A client services agent

At the Hôpital de Sept-Îles, a person was hired to provide interpretation services for English (and Innu and Naskapi) speakers.

Volunteer support (escort, guide)

In Quebec City, the Anglican Diocese offers a support service; some volunteers are able to interpret.

Health passport

The CHSSN has developed a web-based application with basic terminology and information for Anglophone patients.

Professional interpretation

This is ideal, but not often available in English.

Because of the language barriers, the need for emotional and physical support, the loneliness or the age of the patient (children and seniors), many residents of eastern Quebec bring along a support person who can interpret for them.

This person may be a family member, a friend or a neighbour who 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.

Usually the patient covers the cost of the stay for their support person. This may appear to be a reasonable solution to a critical problem, and no doubt in many cases it is very helpful. However, it raises several issues.

First, that person cannot always stay the full length of time needed. The cost incurred can be very high for the patient and/or for the support person.

Second, his or her French may not be fluent, especially for medical terms. This can potentially lead to unreliable translations and misunderstandings.

Third, translating emotionally charged information to a loved one can be very stressful, and research suggests that there are serious ethical issues in doing so. Moreover, medical information can be sensitive in nature or confidential, again raising the question of ethics and confidentiality.

Issue 4: Unfamiliarity with cities and hospitals

Existing strategies

A client services (or liaison) agent

At the Hôpital de Sept-Îles, this person also helps patients find their way around.

Out-of-region medical services

booklet created by the North Shore Community Association and the Agence de santé et des services sociaux de la Côte-Nord can be used to help navigate out-of-region services.

Volunteer support (escort, guide)

In Quebec City, the Anglican Diocese offers a service to help Anglophone patients get around, as well as providing spiritual and emotional support.

Many of the people travelling from eastern regions of the province are unfamiliar with Quebec City and its hospitals. They therefore need practical information and orientation (in English) before leaving, upon arrival and during their stay, including help getting around hospitals.

However, this information is not centralized or readily available. 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 in the cases where they were not admitted to hospital or were travelling as a caregiver, and specifically, an affordable place. This is a significant source of stress, as it can take several calls to arrange and not everyone speaks English. 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.

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.

Issue 5: Costs

"I feel the healthcare wastes too much money on flying individuals to sept Iles or Quebec City. Why not ask the specialists to come a few times a year to service us. Why do we need to travel to them?"

Existing strategies

Regional foundations

On the Gaspé Coast, there are foundations that help residents with the cost of out-of-region services.

Community fundraising

In some communities, people create a Facebook page and neighbours drop off donations at the store to help out with the cost.

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

They can be particularly high for people who must stay a long time, for out-patient stays, for accompanying support persons, and for those who need to fly. Refunds are available for a portion of the expenses, however the remaining amounts can create a financial burden.

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.

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. The length of stay affects:

- the cost for individuals, families and communities
- the likelihood of being alone while dealing with the stress of an illness (since caregivers are not always able to stay for a long time)
- how long a patient experiences these challenges.

"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."

Issue 6: Transfer protocols

"Firstly I wish more services were available locally, second I would prefer to be treated in Montreal where I have family."

Existing strategies

Anecdotally we know that some people choose to go to Montreal and pay the difference for their flights.

Transfer protocols can generate additional stress.

A few respondents mentioned that they were evacuated by air, used medical transport or adapted transport. For people travelling by plane, 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.

Some people also mentioned that they would appreciate being able to choose which city to go to, since some have family in Montreal where they would have more support.

For those travelling by public transportation, a decrease in bus and train services (specifically to the Gaspé Coast) makes it more difficult to arrange for transportation.

Children and vulnerable seniors can be particularly upset when not accompanied by a loved one. The transfer process can be very difficult and stressful for the parents or caregivers, since they cannot accompany the child or senior in the air ambulance.

"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 Quebec City."

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.

Some positive, some negative



"I was very pleased with the overall experience with the hospital staff and doctors. They were very compassionate and helpful."



"It was a very long and very isolated stay. I can speak a bit of French but not really enough to have a conversation. The staff was nice but not really able to communicate due to the language barrier. The cost of lodging was very pricy compared to the amount returned."