Summary Report

Rural, Remote and Northern Women's Health

Policy and Research Directions

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Rural, Remote and Northern Women's Health: Policy and Research Directions Final Summary Report

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Rural, Remote and Northern Women's Health:
Policy and Research Directions

Results from Francophone Focus Groups with Women in Rural and Remote Communities in Canada

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July 2003

Project #4 of the National Rural and Remote
Women's Health Study

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Acknowledgments

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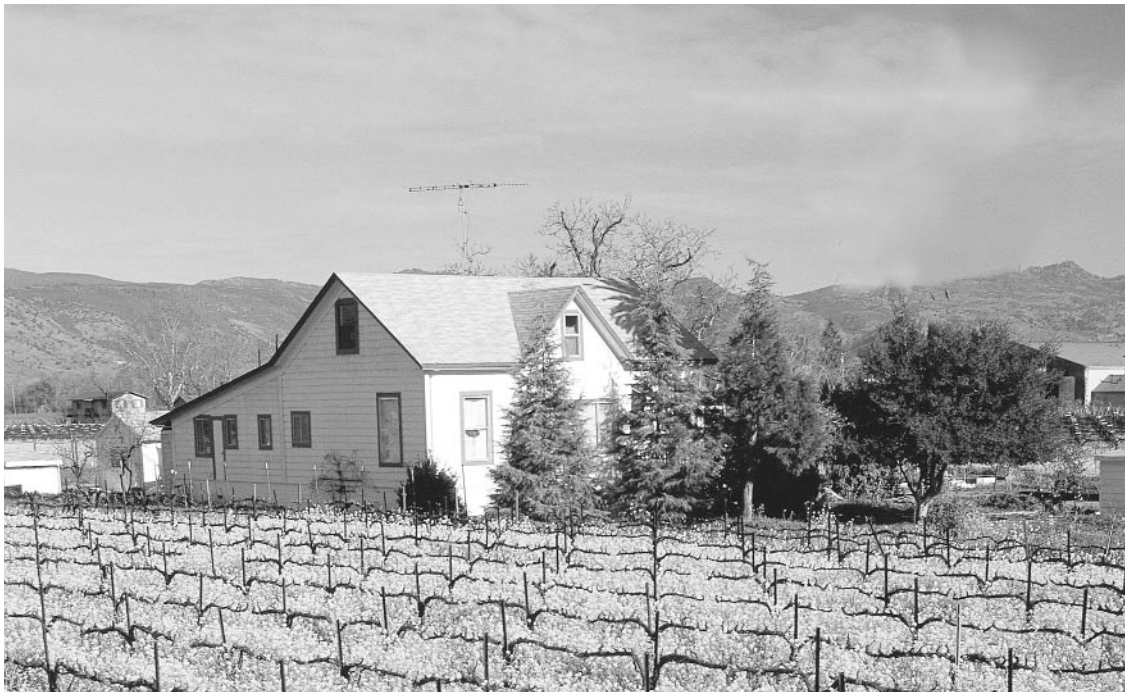


Results from Francophone Focus Groups with Women in Rural and Remote Communities in Canada

Introduction[1]

In the public and political debates across Canada concerning the restructuring and providing equitable access to care to people in rural and remote communities, the consideration of gender and women's health is needed to complete the picture of health needs, service provision and utilization.

In response to this critically important issue, the Centres of Excellence for Women's Health created a National Research Steering Committee on Rural and Remote Women's Health as part of the network of affiliated researchers and community women across Canada. As part of the national project the National Network on Environments and Women's Health (NNEWH) invited *La Table féministe Francophone de concertation provinciale de l'Ontario*, a community partner of NNEWH to facilitate focus groups with Francophone minority women. This report summarizes the findings from six focus groups and one individual interview conducted in French with 30 women, either held in person or by teleconference.

Key Objectives/Research Questions: The key issues which guided the overall National Study of Rural and Remote Women's Health and Health Care in Canada included the following:

In terms of health…

- What are the things that promote the health of women living in rural and remote areas of Canada?
- What are the things that threaten the health of women living in rural and remote areas of Canada?

In terms of health care…

- How satisfied are women with the quality of health care in their area?

In terms of rural/remote living…

- What is it that makes a woman's life rural and/or remote?
- In what specific ways does living rurally or remotely affect the health of women?

In terms of policy to address the above…

- What policy issues are women living in rural and/or remote areas concerned about?
- What do they want changed to better promote their health?

Finally, in terms of the need for further research…

- Are there rural and remote women's health issues about which more information is needed in order to prompt appropriate action?

Methods

Survey and Interview Guide

The Francophone focus groups used the short demographic survey (Appendix D) and a focus group interview guide (Appendix E) developed by Dr. Rebecca Sutherns under the direction of the NRSC and translated by Dr. Christine Dallaire. The Research Steering Committee approved the final versions of the guidelines and questions to be used by facilitators in April 2002, after they had been reviewed for plain language and clarity (see Appendix F for full instructions to facilitators).

Ethics Review was provided by York University under application by Marilou McPhedran and Suzanne MacDonald PhD. In addition, ethics approval for the Francophone focus groups was also obtained through the University of Ottawa with which Dr. Christine Dallaire is affiliated.

Facilitators were expected to adhere to the guidelines and the theme areas of the questions provided. Additional questions were provided to prompt discussion within a focus group if needed. This kind of flexibility was approved of in principle by the Research Steering Committee, according to the principles of responsive qualitative research; that is, as long as the intent and content did not significantly differ from the parameters approved by the ethics review.

Conduct of Focus Groups

All Francophone focus groups were conducted by Dr. Christine Dallaire with the assistance of Mme Guylaine Leclerc from the Table féministe. Each focus group began with an explanation of the study both specifically and within the broader context of the national study. Participants were then asked to sign a consent form (Appendix G) and to complete a self-administered demographic survey. No identifiers were included on the survey and participants were told that completing the survey questions was voluntary and that the information contained therein would be kept confidential.

Following the completion of the survey, Dr. Dallaire would turn on the tape recorder and start with the focus group interview guide questions. Mme Guylaine Leclerc would also

start taking notes of the content of the discussions. During the conduct of the taped group interview, women could ask for any of their comments to be stricken from the record. The focus groups lasted from 1.5 to 3 hours.

Recruitment of participants

The Table féministe recruited Francophone focus group and interview participants through the regional chapters of various national and provincial Francophone women's groups, such as:

Union culturelle des franco-ontariennes
Fédération des femmes canadiennes-françaises
Fédération des femmes acadiennes de la Nouvelle-Écosse
Fédération des femmes acadiennes du Nouveau Brunswick
Instituts féminins (New Brunswick)
Réseau national action éducation femmes
Le Cercle des fermières du Québec
Société Saint-Thomas d'Aquin (PEI) AFEAS
Fédération des agricultrices du Québec
Réseau québécois d'action pour la santé des femmes

Participants were also recruited through Francophone health centers:

Centre de santé Évangéline (PEI)
Centre de santé de l'Estrie (network of Francophone community health centres in Eastern Ontario)

Total number of participants = 30 Francophone women

- Ontario, eight women in two focus groups (Northeastern Ontario: Kapuskasing, Earlton, Chapleau et Casselman; Eastern Ontario: Casselman, Alexandria, Cornwall, Stormont-Glengarry-Dundas townships)
- Maritimes, nine women in one focus group (New Brunswick: Grande Digue, Shediac, Moncton, Grand Barachois; Nova Scotia: Cheticamp) and four women in teleconference focus group (Prince

Edward Island: Wellington, Abram-Village, Summerside)

- West, five women in one focus group (British Columbia: North Vancouver; Saskatchewan: Regina, Gravelbourg; Manitoba: Winnipeg)
- Quebec, three women in one focus group and one woman in a telephone interview (Laurentians: Saint-Jérôme, Beauce: St-Pierre de Broughton; Gaspesie: Sayabec; Montreal)

The PEI teleconference interview involved women from the same geographical community while one of the Ontario focus groups involved health professionals working within the same network of community centers in Eastern Ontario. All other focus groups included women from different regions within the same province (the Quebec focus group, the other Ontario focus group) or women from different provinces (the Maritime focus group and the Western focus group). Our objective was to gather data from Francophone women from a variety of regions (majority-Quebec, majority-local communities within Anglophone provinces, majority-local communities in bilingual province/New Brunswick, minorities) and that represented a diversity of rural experiences (farming, fishing, pulp and paper communities). To limit travel costs of participants, focus groups were held in urban central areas (Moncton, Regina, Montreal, Ottawa). Only one focus group was held in a rural town, in Crysler Ontario.

Commentary on who was in attendance

Since we recruited mainly through women's organizations, interview participants were the members of these organizations, thus they were part of social, professional and/or political network. These women were involved at various levels in local or provincial women's groups, and in some ways they represented the women's leadership of their communities. However, they were mostly involved in the field of social services, health services and family issues (while men are still dominating the municipal and Francophone political leadership).

Other participants were recruited through health organizations. They were health care and service providers (nursing, health promotion) or community organizers for health centers (developing health care programs and services).

Many of the women had different responsibilities and spoke from various perspectives. They were, for instance, involved in women's groups, leading volunteers in social and health care services (school breakfast, meals on wheels, etc.) and members of health care decision-making bodies (hospital/community health center committees and boards).

A few of the women interviewed did not live in rural areas at the time of the interviews but had:

a) lived in rural areas

b) and/or participated as representatives of women's provincial organizations and answered questions in light of their experiences of serving women in rural and/or remote areas and in light of the reported experiences of rural and remote women of their organizations.

While we did not ask questions about participants' cultural or ethnic background, we would hypothesize that most women, if not all women, were of French Canadian or Acadian ancestry and thus shared some basic cultural characteristics.

Commentary on who was not in attendance

Younger women (18 to 35 years old) were not well represented among focus group participants, nor were immigrants and members of visible minorities. Younger women are not well integrated in Francophone women's association as they are, on the one hand, not attracted to what appear to them, at least in rural areas, as being "older" women's groups, and on the other hand, too busy trying to juggle their professional and family responsibilities. We suspect that these women are involved in other types of organizations such as school committees and associations of leisure/sport activities to ensure opportunities for their children. French-speaking immigrants and members of visible minorities have founded women's groups but they are concentrated in urban areas.

We did contact a group of Francophone rural women living with disabilities, but they were not available at the time of the scheduled focus groups.

It is also important to remember that women not involved in community or women's associations were not represented in these focus groups.

Suggestions for improvement

Recruiting through associations provided us with an important network of potential participants. In some cases, names and contact information of rural and remote women were provided to us and we were able to communicate with potential participants. Yet, some women did not turn up despite confirming their attendance. We have found that it is sometimes difficult to get direct access to women since in other cases, the organizations either took on the responsibility of recruiting participants, sometimes successfully but not always (in Quebec for instance) or they simply did not wish to collaborate as they felt the potential rural women concerned about health issues were already busy attending another regional Francophone health meetings (which we were not aware of when the focus groups were scheduled). It would be better to directly communicate with participants even when they are recruited through other organizations and to frequently communicate with the various organizations.

Suggestions to improve the questionnaire for future research

1) Some questions need to be more specific since participants did not know how to answer them (answers varied since the reference–village, region, community–varied)

   a) Do you live in the same geographic area as where you work?

      *Is too vague, perhaps substitute "municipality, village, town" for "geographic area"

   b) If different, what is the approximate population of where you work?

      *Be more specific, perhaps substitute "municipality, village, town" for "where"

2) Questions about the distance to specialist services and alternative health need to be morespecific as well. Either include some blank spaces where women can identify the type of specialist, then the distance to get to his/her services or provide a detailed list of specialist services. The same applies to the question about alternative health service providers.

For these same questions, it might be better to ask for only the distance in km or the time to get to the services. (Unless it is felt that distance in km does not reflect the actual time when considering road conditions when driving.)

Results and Analysis of Focus Groups and Telephone Interviews

The presentation of the data that follows begins with a description of women's demographic backgrounds. Demographic data presented (Figures 1-10) here were drawn from those tabulations completed by Dr. Christine Dallaire and graphics prepared by Karima Hashmani at the National Network on Environments and Women's Health.

This is then followed by a summary of the key themes highlighted by women in the focus groups organized into five broad conceptual categories including their views on: health, health care, rurality, and their recommendations for policy and research. The analysis concludes with general comments about the similarities and differences among participants' responses as well as other issues raised by their responses.

Figure 1

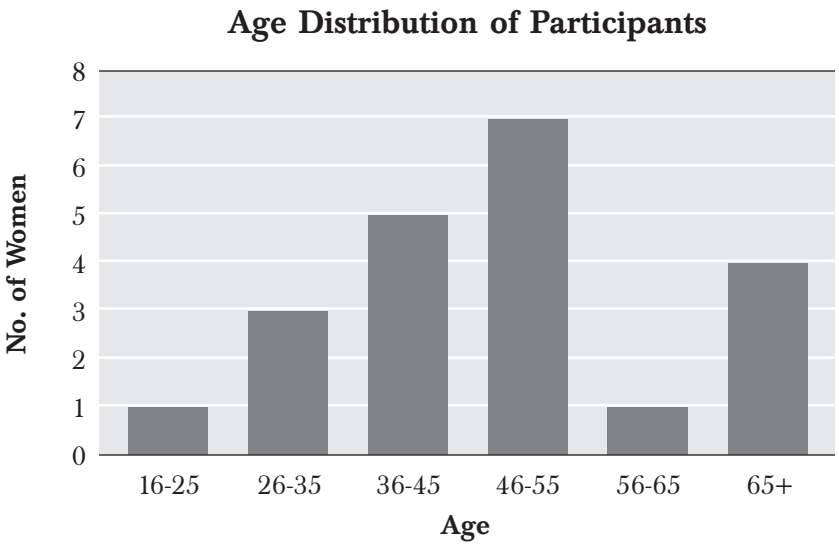
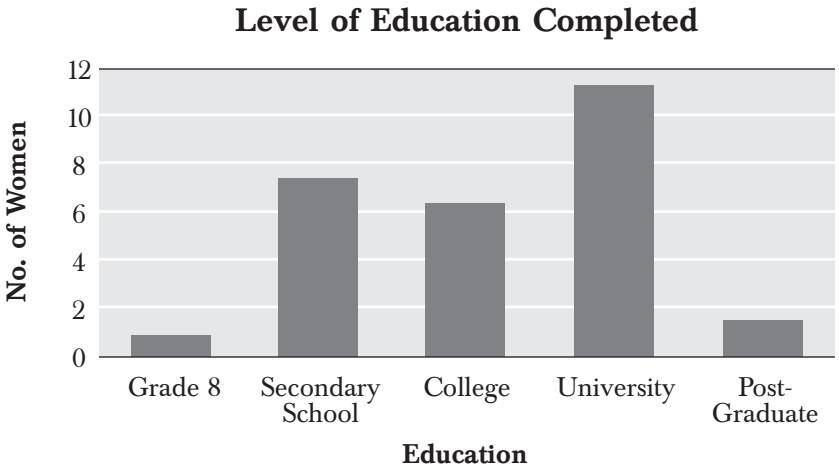


Figure 2



** N.B. Initial data collection identified registered nurse as a completed level of education, and the category has been amalgamated into the college category based on assumption, not a certainty. The university category includes some women that participate in university for the elderly. **

Figure 3

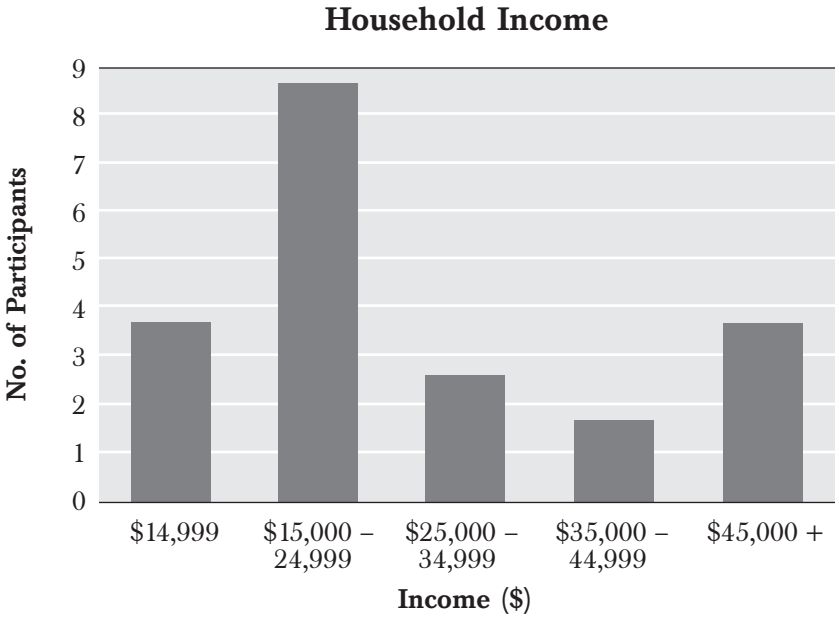


Figure 4

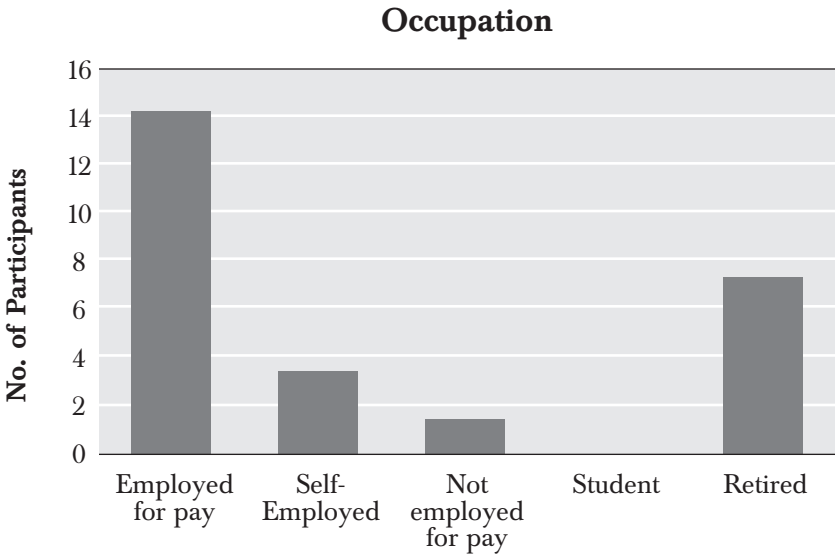


Figure 5

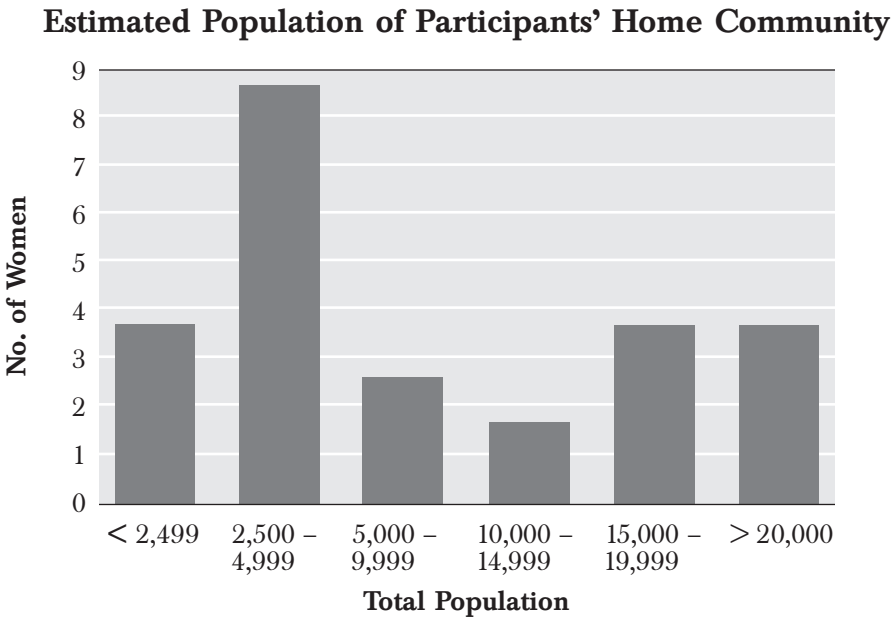


Figure 6

Marital Status

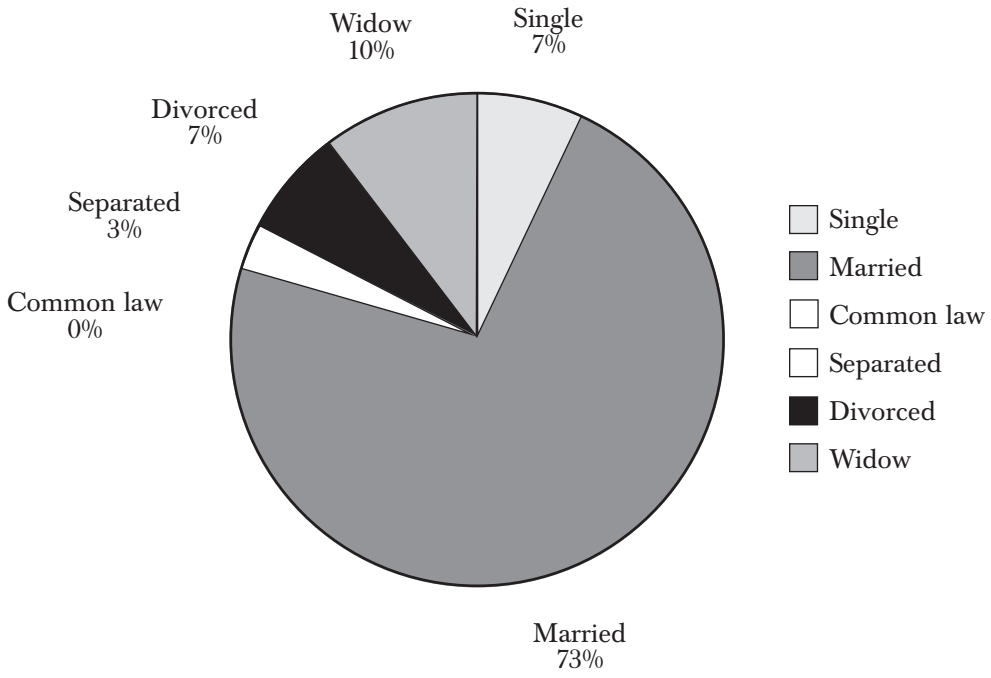
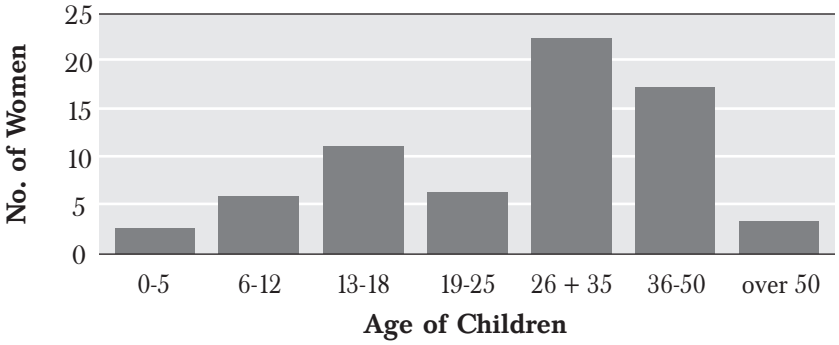


Figure 7a

Age of Participants' Children



Average age of women: 29.03
Medium age range: 19–25

Figure 7b

Number of Children Per Participant

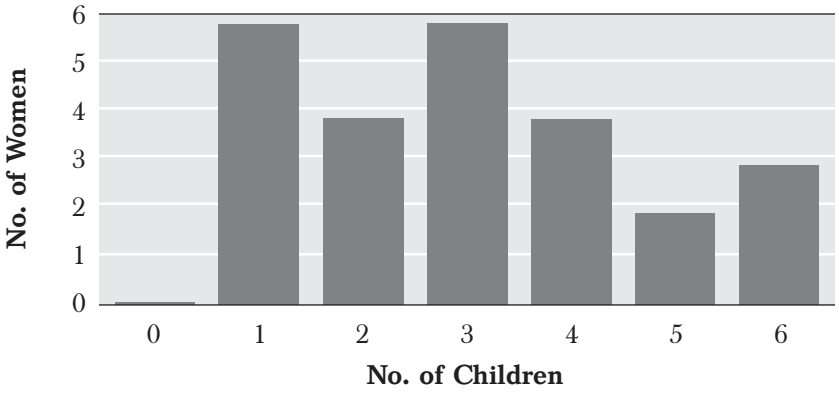


Figure 8a

Number of Participants Who Live and Work in Same Geographic Region

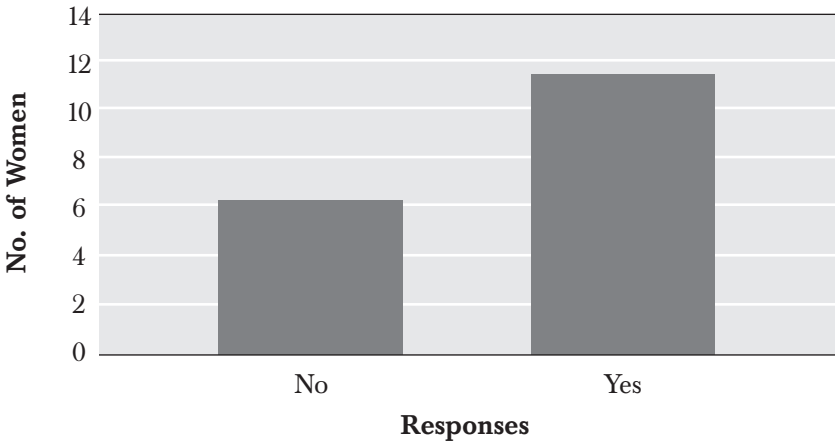


Figure 8b

Distance Between Home and Work

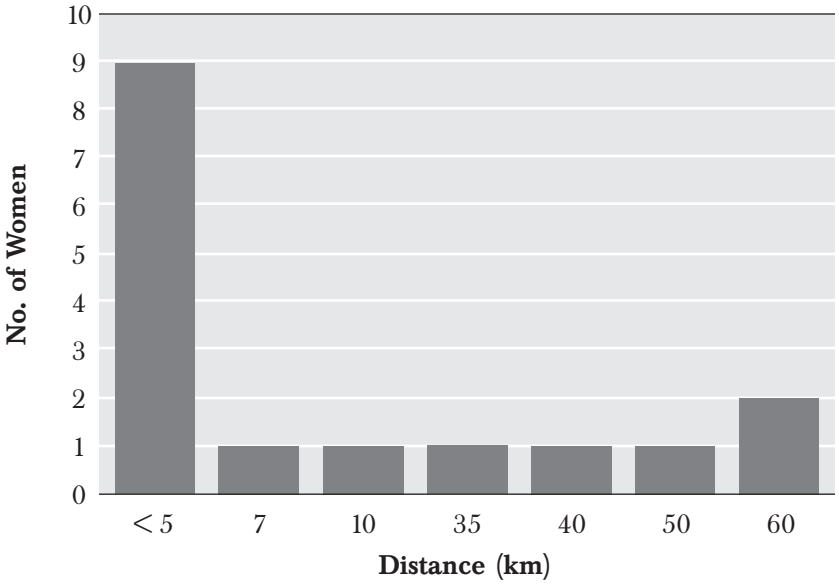
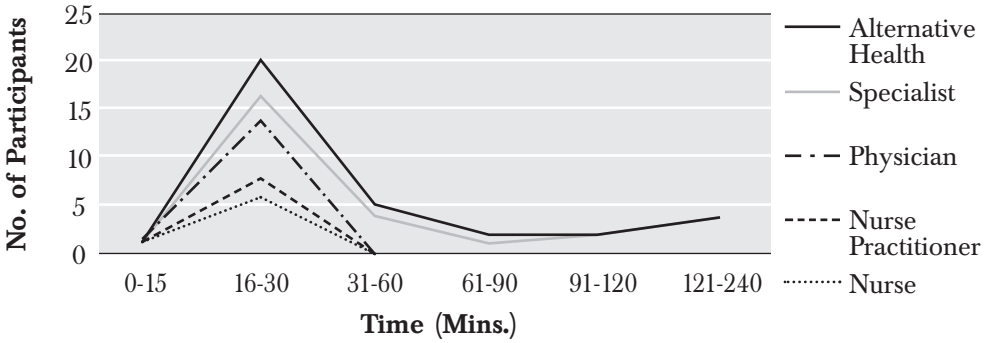


Figure 9a

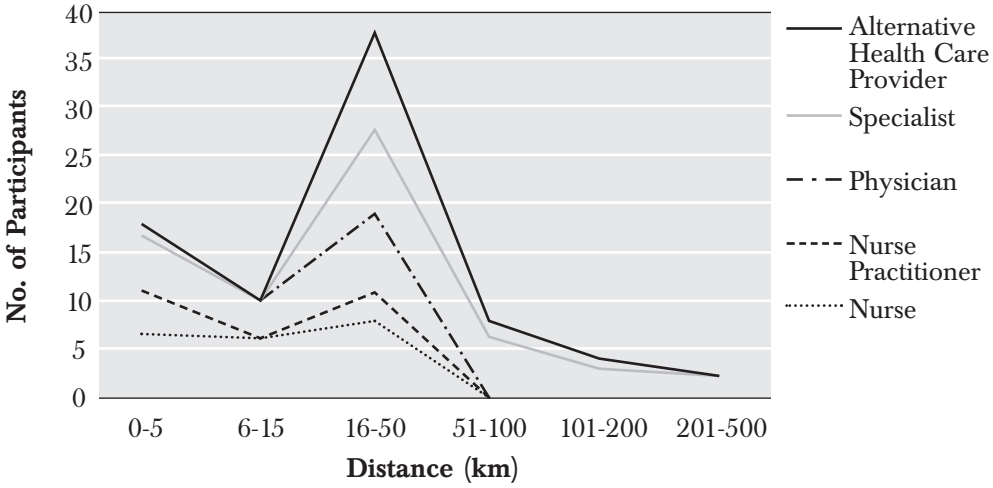
Time Travel to Nearest Health Care Provider



Health Care Providers	Number of Respondents	Average Travel Time
Nurse	7	22
Nurse Practitioner	2	22.5
Physician	6	26.25
Specialist	15	74.17
Alternative Health Care Provider	10	58.75

Figure 9b

Distance to Nearest Health Care Provider



Health Care Providers	Number of Respondents	Average Distance
Nurse	21	26.25
Nurse Practitioner	9	36.67
Physician	20	21.3
Specialist	20	100.71
Alternative Health Care Provider	15	53.18

Presentation and analysis of focus group and interview discussions

For the purpose of this report, results are organized in such a way to correspond to the questions outlined in the focus group guidelines. However, it should be noted that during the actual discussions among participants, answers to different questions did emerge at various points during the interviews, not merely in the order the questions were asked. Thus, the structure of the presentation of the results respects the order of the focus group guidelines, but the answers to the questions are drawn throughout the interview transcripts.

For example, participants' responses concerning the health of women in general

Questions and themes addressed: Health

Table 1 Responses to the question: What assets/resources promote your health/the health of your clients?

Type of advantage	Examples	Further explanation/detail
Assets for women's health in general	Education	"Women are more educated today"
	Knowledge and political and/or community involvement	"Women are now more 'politicized'"
	Awareness women's equity issues	"We talk more about women's equity today"
	Longer lifespan	
	Involvement in the workforce	
	Women are now more conscious of their limits	
	Promotion and access to physical activity programs, services and resources	
	Positive attitude of provincial government to improve provision of French services (PEI)	
Resources for women's health in general	Women's groups	Workshops, forums, information days, colloquiums
		Sharing information, awareness (equity, family, self-esteem, self-confidence, healthy meals, etc.)
		Support, services
		Internet discussion list
	More information is available	Media (television, radio, newspapers, magazines), cereal boxes, etc.
		Internet (i.e. Health Canada Website)

are presented separately from those regarding rural and remote women's health in order to better distinguish and focus on issues particular to rurality. However, during the discussion, the questions regarding the factors that have a positive or a negative impact on women's health in general and on rural and remote women's health were discussed concurrently.

None of the participants had spontaneous answers to the question regarding the factors that have a positive impact on the health of women in general or of women living in rural and/or remote areas. However, once they started identifying such factors, participants did come up with a variety of other advantages/benefits.

It is noteworthy that as all participants were involved one way or another with women's groups, they insisted on the importance of such organizations for sharing information, providing services and promoting women's equity in terms of access to the workforce, developing a greater autonomy and changing attitudes among women, their families, their communities and society at large (perhaps, the change in attitudes are not felt to be fast enough!). It was through their participation in women's groups that participants became more:

a) aware of women's issues and gained access to a wide variety of information/education on issues such as health, family violence, nutrition, self-esteem and financial security

Table 2 Responses to the question: What services promote your health/the health of your clients?

Type of advantage	Examples	Further explanation/detail
Services for women's health in general	More programs targeting specific women's health issues	Breast cancer, mother-daughter walks, programs for young mothers, breast cancer detection programs
	Access to physical activity programs and services aerobics, yoga, Tai chi	Fitness centres and fitness centres specific for women,
	More hospitals and more health services (compared to what was available not so long ago)	CLSC (Quebec), info 24 hrs 7 days/week
		Extramural program (New Brunswick); homecare by interdisciplinary team, 24 hrs, 7 days/week
		Public health programs; health promotion, nurses, dieticians, inspectors, etc.
		Women's shelters
		Centres and institutions for those dealing with mental health problems
		Centres for single mothers
		Larger variety of services (chiropractors, physiotherapists, etc.)

b) politicized and involved in their community (not just in women's issues, but health, schools, elderly, etc.).

Participants acknowledged the advantages of their involvement in women's organizations and recognized that not all women benefit from such networks.

Du côté de l'Association des femmes, dans les dernières années, tout ce qu'il y a à faire avec la violence familiale, la sensibilisation, tous ces projets, le bien-être, toutes sortes d'activités de promotion puis beaucoup sur l'estime de soi, la confiance en soi. Il y a eu beaucoup, beaucoup de programmation de la part de l'Association. À un moment donné, on faisait juste des fashion shows, mais là, c'est beaucoup plus proactif.

For the Women's Association, during the first years, everything that has to do with family violence, consciousness raising, all these projects, well-being, all kinds of promotion activities and lots on self-esteem, self-confidence… There have been lots and lots of activities put forth by the Association. At a given time, we only did fashion shows, but now, it is much more proactive.

Réseau Femmes Colombie-Britannique a un service qui s'appelle l'Inform'Elle, qui est un service d'écoute, de soutien puis de référence qui a commencé initialement pour travailler auprès des femmes violentées mais qui devient un soutien puis un service de références, qui fait beaucoup d'appui et puis qui développe le réseau.

Réseau Femmes in British Columbia has a program called l'Inform'Elle, which is a call-in service that gives support and references. It was initially created to work with women living with violence, but that is becoming more of a support and reference service that gives a lot of support and is developing the network.

Bien, moi, je prétends qu'au niveau des membres de l'UCFO, on est choyées puis on se gâte. Puis on gâte nos membres parce que quand on a des activités en grands groupes, on a des invités puis on va toujours chercher pas mal la crème des invités. Si je prends comme un exemple, nous autres, pour AGRA, j'ai appelé à l'hôpital Montfort. Cinq semaines plus tard, j'ai eu la réponse que j'étais pour avoir une madame Bouchard comme conférencière. Et le thème qu'on voulait développer, c'était la santé mentale.

I think that UCFO members are lucky and spoiled. We spoil our members because when we have large group activities, we have speakers, and we always get the best speakers. If I take for example at our Regional AGM, I called Montfort Hospital. Five weeks later I got the answer that we would have Ms. Bouchard as a speaker. The theme we wanted to broach was mental health.

Table 3 Responses to the question: What barriers/attitudes/ threaten your health/the health of your clients?

Type of disadvantage	Examples	Further explanation/detail
General barriers to women's health	Lack of financial resources	New medication/solutions not financed fast enough
		Cost of medication – For those with no group health insurance – For women when the husband turns 65 (and the women are no longer covered by husbands employer health plan)
		Income (elderly and those receiving social assistance are particularly vulnerable)
	Health system is under funded	
	Health research results/conclusions not implemented fast enough	
	Economic conditions	Precarious employment
		Having to move to find employment
		Contract employment/lack of job security
		Lack of control on one's economic production
	Having to fight to obtain services in French	Having to lobby the government
		Having to claim French services
General attitudes that negatively affect women's health	Women wait before they seek health services	Afraid to be sick
		Wait until it goes away
	Social attitudes and demands of women	Women are too busy and have too many responsibilities
		Who takes care of the caretaker?
	Health discourse focused on medicalization and treatment of disease	While women have a more holistic perception of health; some women do not trust "modern" medicine
	Insufficient communication of information to women	Most information is shared among health professionals/administrators and/or leaders (who are mostly men)
	Women and especially elderly women are not taken seriously	
	Negative attitudes of Anglophone majority towards Francophones	With regards to the needs of Francophones and to the provision of services in French
	Lifestyle	Women in the workforce working too much
		Youths – Diet – Internet – Lack of physical activity

Table 4 Responses to the question: What rules/lack of services threaten your health/the health of your clients?

Type of disadvantage	Examples	Further explanation/detail
General rules that negatively affect women's health	Alternative health and services are not covered by therapeutic medical insurance	Physiotherapy, chiropractors, massage therapy, acupuncture, homeopathy, etc.
	Few or no services in French	When there is translation (either you bring someone, or the hospital provides someone) the patient loses her privacy
		It takes twice as long to get the service in French or when using translation services
		Lack of French-language training for health professionals
General lack of services that negatively affect women's health	Prevention services are ignored, not financed and non-existent	
	Government funding cuts for women's organizations	Can no longer offer services
	Lack of daycare services	For the women that are ill and for caregivers
	Cuts in existing services	To different extent from province to province
	Centralization of services	Less personalized services (Tele-health now replaces regional services that answered needs in a more personalized way)
	Insufficient (or inexistent) support	For sick women
		For caregivers
		For those getting tests, waiting for results,
		After medical intervention
	Waiting lists	

This question certainly elicited spontaneous and numerous answers.

The overall lack of funding for the health-care system and the rising costs of health care were common complaints. Participants also identified situations that particularly disadvantaged women, such as the cost of medication for under 65 year old married women whose husbands are over 65 years old and who no longer benefit from pension medical insurance plans.

Ça revient à dire nos attentes, les attentes que la société met sur nous autres, les attentes qu'on se met sur soi-même, les attentes que notre mari met sur nous autres, les attentes que nos enfants mettent sur nos épaules. Il y a des journées que je me demande comment est-ce que les femmes font pour faire puis tout réussir. Il doit y avoir des manquements à quelque part!

It boils down to voicing our expectations, the expectations society puts on us, the expectations we put on ourselves, the expectations our husband puts on us, the expectations our children put on our shoulders. Some days, I ask myself how women manage and succeed in

everything. There must be some misses somewhere!

Focus group participants also offered many comments regarding the social role and responsibilities women are expected to assume that overburden them and tax their own health. Such roles mostly concern the personal sacrifices of women who take care of family members in addition to being predominantly responsible for childcare and housework, even when they are in the paid workforce.

Il y a un petit aspect qui me dérange peut-être un peu et puis je veux m'assurer qu'on puisse en parler. C'est les femmes qui prennent soin de leurs parents et qui finissent par mettre leur santé en péril parce qu'elles font du travail pour lequel elles ne sont pas formées puis elles prennent soin de personnes qui sont presque plus autonomes du tout. Mais ces [femmes] finissent par être malades elles-mêmes parce qu'elles n'ont pas les outils nécessaires. Et elles n'ont pas la formation nécessaire. Et elles travaillent des heures ridicules sans pouvoir être payées parce que [elles prennent soin d'un] membre de la famille. Donc, je pense que c'est un aspect extrêmement important parce que tu as le côté de la personne même qui est chez elle et puis tu as la personne qui en prend soin qui finit par être dans le système elle aussi. Et puis qui vit dans la pauvreté souvent parce qu'elle ne veut pas se faire payer pour le travail qu'elle fait.

And they work ridiculous hours without being able to get paid because they are taking care of a family member.

There is a small aspect that bothers me a bit but that I want to make sure that we talk about. It is the women who take care of their parents and end up putting their health in jeopardy because they are doing work that they are not trained for and they are taking care of persons that have lost almost all autonomy. But these women end up being sick themselves because they don't have the necessary tools. And they don't have the necessary training. And they work ridiculous hours without being able to get paid because they are taking care of a family member. I think that it is an extremely important aspect because you have the person that is at home and you have the person that takes care of them who ends up also being in the system. And ends up living in poverty because she doesn't want to be paid for the work she does.

Health and Rurality

Many women spontaneously discussed the positive impact of environmental factors, such as better air quality and better access/opportunities for outdoor physical activities.

In addition, participants focused on the quality of social relationships and support networks in smaller communities. These closer ties and community spirit would also translate into safer communities and better interactions with healthcare providers, particularly those who have made a long-term commitment to the community.

Surtout, mais même dans nos petits villages, tu remarqueras que les gens, on doit compter beaucoup sur du bénévolat. Et puis souvent, la vie est quand même plus active. Tu vas retrouver des organismes, des regroupements que tu ne retrouves pas ailleurs. Je vais juste prendre comme exemple après des funérailles, il y a tout un réseau pour recevoir les familles puis ça se fait automatiquement. Mais ça prend des gens, ça prend de l'engagement, ça prend du temps… Et puis tu retrouves plus le mouvement scout dans les petites paroisses et puis l'engagement au niveau du hockey dans les petits centres.

Especially, and even in our small villages, you will notice that people must depend a lot on

Table 5 Responses to the question: In what specific ways does living rurally or remotely positively affect your health or the health of those in your care?

Type of advantage	Examples	Further explanation/detail
Assets specific to living in rural and remote areas	Environment	Air Quality
		Space
		Peaceful
	Lifestyle / Exercise	Exercise, working/spending time outdoors
		Resources to spend time outdoors (ski trails, hiking trails, etc.)
		On farms, outdoor and/or physical work
	Ownership of home	
	Smaller communities/ Geographic proximity	Shorter distance to local services, more convenient; walk within villages/towns; short car rides
	Quality of social relationships	Knowing your neighbors and community members
		Family and social support
		Being involved, volunteering
		Community participation; pull together
	Less Stress	No congestion/traffic
		Pace seems slower
Resources specific to rural and remote areas	Information/ communication	Not many services, but communication is efficient—aware of what does exist in French
Services specific to rural and remote areas	New model of integrated services / Community health centers	More and better access to services
	Quality of care	When a health-care provider decides to establish him or herself in a rural community and actually stays, he/she knows everyone; seem more dedicated and concerned

volunteers. And often, life is more active. You will find organizations, networks that you won't find elsewhere. I'll just take the example after a funeral, there is a whole network that welcomes the families, and that is done automatically. But it takes people, it takes involvement, it takes time… And you will find more scouts in small parishes and the involvement in hockey in small communities.

Pour moi, une grosse force, c'est concentré dans notre région, c'est notre Centre de santé communautaire avec les services en français et des personnes disponibles pour nous aider. Les gens sont connus, le personnel est connu de la communauté, ce qui fait une grosse différence. On accueille des gens et le vouloir d'aider. Alors, je pense que les personnes de la communauté se sentent à l'aise d'aller demander des questions, même si c'est juste une question à l'infirmière publique : « Est-ce que je devrais aller voir le médecin? »

For me, one of our big strengths is, especially in our region, is our Community health centre with services in French and persons available to help us. The people are known, the personnel is known in the community, which makes a big difference. We welcome people and want to help. So, I think that people feel at ease to ask questions, even if it's just a question to the public nurse: "Should I go see the doctor?"

Mais un autre point, moi, je trouve qui est positif, c'est que les gens en milieu rural—que ce soit dans les petites communautés ou sur les fermes—se

connaissent entre eux autres. Donc, il y a les aidants naturels qui sont des appuis, qui font que les gens se rendent service. Les gens s'entraident et puis c'est un point rassurant. Ça, je pense qu'au point de vue santé, ça ôte un stress.

Another point I find is positive is that people living in rural areas, whether it be small communities or farms know each other. So they help and support each other. People help each other and it's a reassuring point. I think that in a health aspect, it takes away stress.

Rural women noted that some programs have been developed to provide better access to health-care services.

Le service peut-être le plus spécifique pour les femmes, il faut qu'on le mentionne, c'est la mammographie ambulante qui va d'une communauté à l'autre à tous les deux ans. Ça fait que ça, c'est un atout. Dans notre communauté rurale, à tous les deux ans, le gros trailer arrive pour une semaine, deux semaines. Alors, c'est que ça permet quand même aux femmes qui ne conduisent pas, puis le service d'autobus est beaucoup plus questionnable depuis à peu près cinq ans, alors, il n'est pas aussi régulier. Alors, il y a tout ça qui joue. C'est un positif, et je sais que dans ma communauté, ça eu des effets bienfaisants. Des jeunes femmes qu'on a trouvé tout de suite qu'elles avaient le cancer du sein puis elles avaient 32, 35 ans, qu'on n'aurait pas, probablement, si la roulotte n'était pas venue, qu'elles n'auraient peut-être pas été se faire vérifier aussi vite.

Maybe the most specific service for women, we have to mention it, is the travelling mammography that goes from one community to the next every two years. That is a plus. In our rural community, every two years, the big trailer arrives for a week or two. So, it gives the women who don't drive, and the bus service has been much more questionable for the last five years, so it isn't as regular. So all of that has an effect. It's positive, and I know that in my community, it has had positive effects. Young women whom we found out right away had breast cancer at 32, 35 years, that we probably wouldn't have found if the trailer hadn't come, they wouldn't have got checked as quickly.

They also praised the model of integrated services for minority Francophones or the Québec CSLC model. However, these integrated French-language services are certainly not common or generalized throughout the country. What is important from the interviews is that women feel that the services that do exist are accessible (whether they are in French or not) but these services are very limited.

Les one-stop shop où les personnes peuvent parler à un ergothérapeute, une physiothérapeute, une nutritionniste, une infirmière en santé publique, d'aller de kiosque en kiosque pour aller chercher de l'information.

The one-stop shops where people can talk to an occupational therapist, a physiotherapist, a nutritionist, a public health nurse, to go from kiosk to kiosk to get information.

For me, one of our big strengths, especially in our region, is our community health centre with services in French and persons available to help us.

Table 6 Responses to the question: In what specific ways does living rurally or remotely negatively affect your health or the health of those in your care?

Type of disadvantage	Examples	Further explanation/detail
Barriers specific to rural and remote	Distance	Extra financial cost
		Stress
		Far from decision-makers
		Having to take days off from work to access services
		Having to find childcare
		To avoid the complications of the travelling, will wait longer before seeking services (but then it might be to late)
		Waiting lists for appointments with a specialist (patients might just give up)
		Having to leave your hometown to get treatment (i.e. cancer) or services – Loss of social support – Extra costs for those that come to help you
		Weather/seasonality (because of the distance to the services and risk of accidents when travelling); canceling appointments because of weather means that you are back at the bottom of the waiting list
		To Francophone services (general or specialized)
		High food costs (fruits, vegetables, etc.)
	Urbanization/extended family leaving	Distance from children and family members – Less family members left in the area, younger ones moved away – Children leave to establish themselves in urban areas This is hard on women's morale and emotional/mental health
	Having to leave rural areas to get closer to specialized services	Elderly people will move to the city
	Accessibility for people with physical constraints	Wheelchairs
	Housing	Less specialized housing for the elderly, but an aging population in rural areas
		High cost of specialized housing/centers for elderly (no income left)
		Less specialized housing for people with disabilities
		Substandard housing
	Lack of resources for Francophones	Institutions, organizations, etc.

Table 7 Responses to the question: In what specific ways does living rurally or remotely negatively affect your health or the health of those in your care? (continued)

Type of disadvantage	Examples	Further explanation/detail
Barriers specific to rural and remote	Seasonal employment	Cannot leave for specialized services during working period
		Put off seeking services until it becomes urgent/emergency
		Low annual income
	Isolation	Mental health issues/loneliness
		Lonely elderly widows (who do not drive)
		Difficult to integrate in a rural area when you are not "from there", especially for women at home with no means of transportation
	Economic hardship in single industry communities	Limited employment for women
		Low income for women
	Farming	Work is never done; more than 40-hour weeks
		Occupational accidents and injuries
	Compromised confidentiality	Health professionals and other health care employees know all the patients; stigma related to specific health issues (i.e. mental health, contraception) so patients prefer to not seek medical help in their communities
	Low levels of education	Illiteracy
Attitudes specific to rural and remote	Social expectations of women	Women's responsibilities for their family and larger social network (even more pronounced and conservative in rural and remote areas)
		Too much is expected of women as caretakers
		Staying in bad relationships; affecting self-esteem
	Religious and moral beliefs or expectations of girls and young women	Lack of education in sexual issues (taboo topics: venereal diseases, contraception, abortion, homosexuality)
		Lack of services for pregnant teens
Rules specific to rural and remote	Reimbursement for travel to visit specialists	Is not offered in all provinces
		It takes a long time to get the reimbursement cheque
		Does not cover all costs

Table 8 Responses to the question: In what specific ways does living rurally or remotely negatively affect your health or the health of those in your care? (continued)

Type of disadvantage	Examples	Further explanation/detail
Lack of services specific to rural and remote	Lack of information	To deal with specific health issues/ problems (i.e. how to live with breast cancer)
		About local/rural populations to better plan health services
	Lack of health services	No access to specialized support groups (i.e. cancer)
		Lack of mental health services in French
		Long waiting lists for specialized care (when some specialists do travel to rural areas)
		Lack of health-care providers (especially family physicians but also nurses, physiotherapists, etc.); problems of recruitment and retention
		Lack of specialized services (dietician, etc.)
		Patients are hostage to one health professional's treatment plan; no chance for a second opinion
		Lack of coordination between health agencies
		Loss of specific local services as a result of provincial health restructuring and centralization of services (i.e. provincial tele-health rather than regional services)
	No transportation services	For women who do not drive or own a car
		When there is only one car for the family (used by the husband to get to work and the women has to travel away for health services)
		Public transportation: nonexistent – no train – few buses and only for long distances; not for travel within the community or within the region – flights are expensive
	Lack of services in French	Dispersed Francophone population, thus less services
		Health professionals who can speak in French do not advertise it
		Lack of French-speaking health professionals
		When there are Francophone services, they are soon overcrowded
	Lack of childcare services	Insufficient regulated childcare spaces Low quality of childcare services

Table 9 Responses to the question: In what specific ways does living rurally or remotely negatively affect your health or the health of those in your care? (continued)

Type of disadvantage	Examples	Further explanation/detail
Lack of services specific to rural and remote	Lack of prevention services or greater distance to existing services	Less choices for physical activity
		No fitness centres, pools, etc.
		Less organized sports
	Quality of services	Not equal to that in urban areas – No choice in selecting specialist or doctor – Getting a service depends on who you know
		Specialists are not necessarily cognizant of the distance patients have to travel to see them – Travel to get results, after a previous travel for the tests, and be told nothing is wrong – Different trips for different tests rather than doing them all at once

All the problems identified are linked to the greater distance women have to travel to access specialized health services and transportation problems. These were the first answers of participants to this question. They emphasized the financial cost as well as the stress and complications that travelling long distances and separation from one's family and social support impose on rural and remote Francophone women. The significant and inevitable impact of distance from specialized health-care providers was certainly the one issue that created a consensus among the women interviewed. (Access to local health services in terms of distance was not seen as a problem when travelling to town and in town. When one has a driver's licence and access to a car this is fairly easy in small towns–no traffic, plenty of parking…)

Les gens de milieu rural sont envoyés en avion à la ville pour des chirurgies, pour n'importe quoi qui est un peu plus spécifique. Et puis ils sont ici, tous seuls, à combattre un cancer en milieu urbain, à combattre un cancer. Y'a rien. Et quand on met la langue là-dedans, bien ils arrivent ici en anglais, et c'est pas mieux non plus.

Rural people get sent by plane to the city for operations, for anything that is a bit more specific. And they are here, all alone, fighting a cancer in an urban environment. There's nothing. And when we factor in language, well they get here in English and that's not any better.

Et puis vivre ça seul, parce que souvent, la famille n'a pas les moyens de les suivre avec leur thérapie. C'est beaucoup. C'est dur sur la santé des personnes. Ça leur enlève le goût de vivre, le support moral qui tombe sur leur famille.

Évidemment souvent c'est les femmes qui donnent cet appui. Donc, elles doivent perdre du temps de travail. Elles doivent payer des frais de garderie pour pouvoir suivre la personne, pour les enfants. Donc, il y a toujours, ça finit toujours par tomber un peu du côté financier ou du côté social sur les épaules de la femme.

And living that alone, because often, the family can't afford to follow them during their therapy. It's a lot. It's hard on people's health. It takes away their will to live, the moral support that comes from the family.

Obviously, it's often women that give this support. So, they have to take time off work. They have to pay the babysitter to be able to follow the person, for the kids. So it always ends up by falling on women's shoulders financially or socially.

L'inquiétude, le stress. Et on va retarder plus. Ah, on va attendre. Il faut que j'aille en dehors de la ville. On va attendre et on va voir.

***Modératrice** : Le déplacement est fatigant?*

Oui et de laisser notre milieu pour te dépayser complètement.

Et là, on aggrave notre cas et puis quand on décide bien souvent, il est trop tard parce qu'on avait pas les soins sur place.

On prend des chances et on joue avec notre santé.

Worries, stress. We will wait longer. Oh, we will wait. I have to go out of town. We will wait and see.

Facilitator : The travelling is tiring?

Yes and to leave your environment and be in a totally unknown place.

And then, we make our case worse when we finally decide, it's too late because we didn't have the services in the community.

We take chances and play with our health.

Une autre chose que chez nous, on se rend compte, c'est quand il faut que tu ailles voir un spécialiste, c'est toujours loin. Et puis ces spécialistes n'ont aucun respect pour toi comme patient, le fait que tu as [fait] une grande distance. Ils peuvent te faire retourner pour cinq heures de route pour te donner le résultat de tes tests et puis pour te dire qu'il n'y avait rien, tu n'avais pas de problème. Tu vas être dans le bureau du médecin quelque chose comme cinq minutes et puis tu as voyagé cinq heures pour y aller mais il faut que tu retournes chez vous cinq heures. Ça fait que ça, c'est un petit peu de sensibilisation au niveau des bureaux de spécialistes.

Another thing that we notice at home, is that when you have to see a specialist, it's always far. And certain specialists have no respect for you as a patient, the fact that you have travelled far. They can ask you to do a five-hour drive to give you a test result and to tell you that there wasn't anything, that you didn't have any problem. You'll be in the doctor's office for something like five minutes and you travelled five hours to get there and you have to travel another five hours to go home. That needs a bit of consciousness raising in specialist's offices.

The problem of lack of services and health-care professionals in their local communities was also acutely felt, as a result of the distance from larger service centres and of the low density of rural and remote areas.

C'est ça, et on ne peut même plus avoir notre médecin de famille chez nous. On n'a même plus accès à un médecin de famille. Rares sont les personnes. Je dirais qu'il y a peut-être 25 pour cent seulement de la population de notre région qui a un médecin de famille. Là, aujourd'hui, tu vois lui et demain, tu vas aller voir l'autre et puis là, ils te disent, bien tu iras à l'urgence. Mais là, à l'urgence, c'est quatre heures d'attente.

That's it and we can't even get a family doctor at home. We don't have access to a family doctor any more. Rare are the people. I'd say that there's only about 25 % of the population in our region that have a family doctor. Today you see him and tomorrow you see another and then, they'll say that you should go to the emergency. But then, at the emergency, it's a four hour wait.

… parce qu'on a déménagé puis ça nous a pris presque trois ans avoir un médecin de famille. Puis même avec les médecins qu'on voyait ici qui essayaient de nous en trouver, ils avaient pas les moyens de [nous trouver quelqu'un].

…because we moved, it took us almost three years to get a family doctor. And even the doctors that we saw here that tried to get us one didn't have the means to find us one.

Moi, je te dirais qu'il y a un manque de services. Il y a des listes d'attente si tu veux te faire voir en santé mentale. Nous autres, on ne prend plus de clients en santé physique. On est à capacité. (…) Si tu veux des services, surtout un service—comment je pourrais dire ça—des services spécialisés, que ce soit un spécialiste que tu veux voir, tu ne peux pas le voir en dedans de deux semaines. Donc, il faut que tu attendes, être sur une liste d'attente. Tu vas attendre ton rendez-vous. Tu veux avoir un scan : tu vas attendre six semaines ou deux mois, trois mois avant d'avoir ton rendez-vous.

I'd tell you that there is a lack of services. There is a waiting list if you want to see someone in mental health. We don't take any more patients in physical health. We're at top capacity. If you want services, especially a service—how can I say that—specialized services, whether it be a specialist that you want to see, you can't see him within two weeks. So, you have to wait, be on a waiting list. You'll wait for your appointment. You want a scan: you will wait six weeks

or two months, three months before you get your appointment.

Et moi, ça me fait peur parce que nous, on arrive et le monde sont vieillissants. Les enfants sont aux prises. Et là, tu arrives et puis des fois, moi j'y pense. Je me dis « Q'est-ce qui nous attend? Qu'est-ce qui nous attend? » Parce que veut, veut pas, ça ne sera pas facile. (…) Oui, je suis à la retraite. Mon mari aussi. Et puis c'est un autre stage. Et quand tu es en santé, ça va bien. Mais là, et quand tu es aidante puis tu vois tout, tout, tout ce qui se passe, tu dis « Ah, qu'est-ce qui nous attend, nous autres, au point de vue… » À tous les niveaux, au point de vue aidante, aider et puis aussi au point de vue médical. Il manque de tout, là. Il manque des infirmières, il manque de spécialistes, manque de médecins.

And me, it scares me because we are all getting older. The children are caught. And then, you get there and sometimes, I think about it. I tell myself, "What is going to happen to us?" Because whether we want to or not, it's not going to be easy… Yes, I am retired. My husband too. And it's another step. When you're healthy, everything goes well. But when you are a caregiver and you see everything that is going on, you say "What's it going to be like for us …" In every way, as a caregiver, help and also medically. Everything is missing. Nurses are missing, specialists are missing, doctors are missing.

The issue of distance is compounded by the problem of lack of alternative modes of transportation.

Many women also evoked the problem of distance in terms of distance from family members and particularly their children who leave rural and remote areas to work and live in cities.

Deuxièmement, je pense que l'autre aspect négatif, c'est qu'en vieillissant, il y a moins de famille autour. Nos enfants ne peuvent pas rester dans les communautés rurales. Alors, eux manquent le lien familial. Mais nous, je fais juste me comparer, moi, je suis dans la même communauté que ma mère et puis c'est moi qui s'occupe de voir que les choses se fassent pour sa santé. Mais j'ai six enfants puis j'aurai pas un enfant dans ma communauté qui va faire le suivi vraiment parce qu'ils vivent ailleurs. Peut-être que je vais être chanceuse puis il y a quelqu'un qui va revenir. Il y a toujours des possibilités parce qu'il y a quand même des choses qui pourraient les ramener, mais c'est pas probable. Et puis ça, c'est un élément qui manque. Alors, il y a l'ennui je pense surtout des femmes aînées parce qu'elles vivent plus longtemps. La seule chose qui sauve, c'est le réseau d'amitié et de communauté.

Secondly, I think that another negative aspect is that as we get older, there is less family around us. Our children can't stay in rural communities. So they lack the family ties. But we, I am just comparing myself, I am in the same community as my mother and it is me who looks after her health needs. I have six children, but I won't have one in my community to follow up because they live elsewhere. Maybe I'll be lucky and someone will come back. There's always a possibility because there are some things that could bring them back, but it's not likely. And that is a missing factor. So there is solitude I think, mostly for elderly women because they live longer. The only thing that saves is the network of friends and the community.

Éloigné de vos enfants. Ils sont jeunes. Ils partent à 17, 18 ans.

Oui, et il n'y a pas vraiment… j'ai pas d'espoir de les revoir à ###. Y'ont tout fait des métiers que je pense pas qu'ils peuvent revenir à ###. (…) Il n'y a pas d'occasion pour les jeunes de revenir, même s'ils font les métiers qu'ils pourraient œuvrer dans la région. Il n'y a pas de travail pour eux.

Far from your friends. They are young. They leave at 17, 18 years of age.

Yes, there is not really… I don't have any hope to see them again in ###. They all have careers that I don't think that they will be able to come back to ###. … There is no opportunity for youth to come back, even when they have careers that they could do in the region. There's no work for them.

Conservative attitudes regarding sexuality prevent young women from accessing health services.

Si je peux encore rajouter quelque chose, je pense qu'il y a les problèmes des tabous un peu parce que tout ce qui touche à la santé de la femme aussi, la contraception, les maladies vénériennes, juste ce côté-là. Et ce que j'entends des jeunes femmes, c'est que dans une communauté rurale, tu ne sens pas que tu as l'anonymat puis la confidentialité que tu

as en ville où tu peux aller dans une clinique où ton médecin le sait même pas. Tu vas quelque part qu'il n'y a pas nécessairement dans la communauté rurale. Elles n'iront pas, ce qui peut causer des gros problèmes. Ou elles n'iront pas nécessairement chercher certains services. Puis elles n'ont pas les moyens ou elles n'ont pas la disponibilité de pouvoir se déplacer pour aller chercher. Et quand elles y vont, des fois il est un petit peu trop tard. Donc, il y a cette inquiétude. Elles ne seront pas prêtes à organiser quelque chose non plus, une session d'information, justement à cause de ce tabou encore à parler de certains sujets.

If I can still add something, I think that there are problems, taboos a bit because everything that touches women's health, also, contraceptives, venereal disease, only that aspect. And what I hear from young women is that in a rural community, you don't feel that you have the anonymity and the confidentiality that you have in the city where you can go to a clinic and your doctor doesn't even know about it. You go somewhere that does not necessarily exist in a rural community. They won't go, which can cause big problems. Or they won't necessarily get certain services. And they don't have the means or they don't have the possibility of going to get it. And when they go, sometimes, it's a little bit too late. So, it's a worry. They wouldn't be ready to organize something either, an information session, because it's still taboo to speak about certain subjects.

Rural and remote areas are often marked by economic hardship, often associated with the fact that these are single-industry communities.

L'économie, dans les régions rurales et éloignées, l'économie n'est pas bien, bien… Par chez nous, on vit du tourisme et de la pêche. Deux industries qui fonctionnent juste à l'été. L'hiver, c'est la majorité, la grande majorité des personnes sont sur le chômage.

The economy in rural and remote regions, the economy is not very, very…. In our region, we live off tourism and fishing, two industries that only operate in the summer. In the winter, the majority, the large majority of people are unemployed.

In such areas, there are limited employment opportunities for women and when they can join the workforce, their incomes are low. Women are thus less autonomous and more dependent on their husbands and partners. In such economic and family situations, problems of violence against women/family violence can develop.

Smaller communities with limited services and programs do lead to rural women's more frequent community involvement, but this is in the context of need and pressure to take on more responsibilities because if you do not do it, no one else will and the service/activity will not exist. In these circumstances, women's higher participation in organizing community services and events is also associated with social expectations of women. As a result, volunteers experience burnouts.

C'est très vrai. Puis spécialement dans des milieux minoritaires, il y a beaucoup, beaucoup, beaucoup de bénévolat. Puis encore là, le bénévolat est

For a community that works a lot on volunteers and their involvement, it's even harder for the women of these rural regions because they know that if they don't get involved, it means that there won't be any services.

souvent pas valorisé. Puis dans presque trois-quarts du temps, c'est des femmes qui mènent ces organismes. Si je regarde comme les levées de fonds qu'ils ont faits ici pour bâtir le foyer pour les personnes âgées, le trois-quarts des personnes sur le comité, c'était des femmes qui travaillaient pour ça. Beaucoup des choses, des regroupements, toutes les églises, les comités de bien-être et toutes ces choses, c'est toutes des femmes qui sont membres de ces organismes pour aider les organismes de charité. Pour une communauté qui marche beaucoup sur le vouloir des bénévoles puis la participation des bénévoles, c'est encore plus taxant pour les femmes dans des milieux ruraux comme ça parce qu'elles savent si elles ne s'impliquent pas, ça veut dire qu'il n'y aura pas de services. Puis pour faire des levées de fonds en milieux ruraux, c'est beaucoup plus difficile. Encore là, pour les femmes qui veulent des services pour leurs enfants ou des choses, c'est souvent que ça veut dire des efforts additionnels pour avoir accès à un service que des gens dans les villes prennent, ce qu'ils peuvent avoir accès gratuitement.

En conclusion, c'était si on regarde nos communautés, tout ce qui a affaire avec les services à la famille ou le bien-être de la famille en général, c'est les femmes qui mènent les dossiers. Quand on parle de décision politique, c'est encore mené par les décideurs principaux qui sont encore les hommes dans les dossiers, là. Mais quand on parle de bien-être de la famille en général, c'est les femmes qui sont impliquées.

It's true. Especially in minority environments, there is a large need for volunteers. And even then, volunteers aren't considered important. And three quarters of the time, it's women that lead these organizations. If I look at the fundraising that they have done to build the nursing home here, three quarters of the people on the committee were women who were working for that. Many things, networks, all the churches, the well-being committees and many other things, it's all women who are members of these organizations to help these charities. For a community that works a lot on volunteers and their involvement, it's even harder for the women of these rural regions because they know that if they don't get involved, it means that there won't be any services. And to do fundraising in rural regions, it's much more difficult. Even then, for women who want services for their children or things, it often means that additional efforts to have access to a service that people in the city take, that they can have free access to.

In conclusion, if we look at our communities, everything that has to do with services for the family or the well being of the family in general, it's the women that take the lead. When we speak of political decisions, it's still led by main decision makers that are still men in these fields. But when we speak of the general well being of the family, it's women that are involved.

D'abord, les personnes qui font beaucoup de bénévolat sont de notre âge. Veut, veut pas, on s'épuise à faire du bénévolat. Pourquoi? Et nous autres, on le vit et les autres organismes aussi. Le monde ne veut plus… Il n'y a plus de monde qui veut s'impliquer et prendre des postes et tout ça. Pourquoi? Parce qu'ils ne sont plus capables. Ils sont épuisés. Tu as tout le phénomène, tu es aidante chez vous puis autant que tes parents, tes enfants aussi qui te demandent beaucoup. Bon bien là « Pourrais-tu venir garder? Il faut que j'aille avec une chez le dentiste. Il faut que j'aille… » Tu as tout ça. Moi, ce que je dis souvent à ma mère, je dis à l'âge que j'ai aujourd'hui, toi, tu partais avec papa, tu nous appelais : « Bon, je pars pour deux, trois jours. Inquiétez-vous pas. » Mais là, nous autres, on peut pas le faire, ça. Tu le fais, mais tu te sens toujours coupable parce que tu sais que ta mère a besoin d'aide.

First, the people who volunteer a lot are our age. Whether we like it or not, we burnout by volunteering. Why? And we live it and other organizations too. People don't want to …. There are more people that want to get involved and take positions and everything. Why? Because they can't any more. They are burned out. You have the whole phenomena, you are a caregiver at home and as much as your parents, your children ask a lot of you too. Well, "could you come babysit? I have to bring one to see the dentist. I have to go…" You have all of that. What I often tell my mother, that at the age I'm at, you would leave with dad, you would call us : "Well, I am leaving for two, three days. Don't worry." But now, we can't do that. You do it, but you always feel guilty because you know that your mother needs help.

Table 10 Responses to the question: When you think of living in a rural area, what comes to mind?

Rurality: Small communities—low density	Examples	Further explanation/detail
Positive aspects	Simple life	
	Own home	House paid off, elderly stay longer in their house
	Freedom	
	Peace	Compared to noise, sirens, traffic and people in the city
	Serenity	
	Tight-knit communities	Cooperation Community life/feeling
	Fresh air	
	Open or green space	Countryside, fields, open land
		Ocean
		Big yards
		Forest
		Distance between houses and neighbours
	Security	Compared to rate of crime and violence in urban areas
	Different mentality/ experiences than in the city	A place to raise kids where they will not be exposed to "urban problems"
	Farms	Real cows, animals
Negative aspects	Lack of privacy	
	Less services	Water, sewers, etc.
	Having to get involved	Volunteer burnout If you don't do it, it won't happen
	Compromises	Compromise easy access to a wide variety of services in order to gain the positive aspects of rurality

Distinction between rural and remote regions

Rural: Less populated areas (villages, small towns). Less services.

Remote: Geographic distance from major service centers/specialized services.

Nous autres, quand on part de [notre village], on a juste une direction à aller. Nous autres, à côté du village, c'est les montagnes. Il y a des montagnes et des montagnes et des montagnes. Puis de ce côté ici, c'est la mer. Puis de ce bord-là, c'est le parc national puis on n'a pas accès au parc national. Quand on part, on peut toujours aller par-là. Le sud-ouest, tout le monde va par là. Puis c'est dispendieux pour nous autres qui avons une famille parce que si on a des enfants qui jouent du hockey, il faut toujours voyager loin. Si on se déplace pour des réunions, c'est loin. Les médecins, c'est loin. Nous autres, la vie nous coûte toujours deux et trois fois plus que les personnes qui vivent dans la région urbaine, par exemple, où leurs enfants peuvent jouer au hockey dans un petit rang de peut-être 10, 15 minutes de tous les côtés. Puis ça peut aller à l'université une heure au plus,

Table 11 Responses to the question: When you think of living in a remote area, what comes to mind?

Remote: Distance from service centres	Examples	Further explanation/detail
Positive aspects	All the same as for rural areas	
	Beautiful and pristine region	
Negative aspects	Isolation*	Far from services
		Far from services in French (or from other Francophones)
		Only one place/direction to go
		Everything is too far
		Car pooling or other arrangements otherwise can't work
	Cost of living is more expensive	Have to travel for everything: sports, university, health services
	Children leave	When kids leave for university, they don't come back

*Relative: depends on the characteristics of the woman (does she drive, does she have access to a car, etc.) and of the felt/perceived needs

puis c'est rendu à l'université. Nous autres, moi, les miens, c'est à l'université de Moncton, Mount Alison à Sackville, Halifax. C'est deux jours. C'est une journée pour y aller et une journée pour s'en revenir : les hôtels, les restaurants, c'était très dispendieux. Nous autres, la vie [dans notre village], c'est dispendieux.

When we leave our village, there is only one direction to go. Beside the village there are mountains. There are mountains and mountains and mountains. And on this side, it's the ocean. And on that side, it's the national park and we don't have access to the national park. When we leave, we can always go that way. Southwest, everybody goes that way. And it's expensive for us that have a family because if we children that play hockey, we always have to travel far. If we travel to meetings, it's far. Doctors are far. Life always costs us two or three times what it costs people that live in the city, for example, where their children can play hockey on a road 10, 15 minutes away in every direction. And they can go to university an hour at most, and they're at the university. Mine are at Moncton University, Mount Alison in Sackville, Halifax. It's two days. It's a day to go and a day to come back: hotels, restaurants, it was very expensive. Life in our village is very expensive.

In some cases, remoteness can be experienced in larger communities (population of up to 10,000), even if those who live there do not consider themselves rural, because of the limited available services and the long distance one must travel to obtain specialized services.

Mais même le rural, dans ma tête à moi, a complètement une différente connotation parce que pour moi, tu es rural même si tu es dans un village qui est rural parce que tu es loin des services. Même je dirais que si je prends ma ville, tu as des services de base. Mais l'effet que tu es moins de 10 000 de population ou si tu es dans la ville voisine, qui est à environ 6 000 de population, souvent tu as un chirurgien mais pas d'anesthésiste ou tu as un anesthésiste mais pas de chirurgien. Ça fait que ça, ce sont des réalités de milieu semi-rural qui n'a pas assez de monde pour faire vivre tout ce beau monde-là. Parce que c'est pas comme quand tu es proche d'un grand centre, il va faire trois jours chez vous puis trois jours dans son grand centre. Mais là, tu es assez rural qu'il ne vient pas chez toi.

But even the rural, in my mind has a different notion because for me, you are rural even if you are in a village that is rural because you are far

from the services. I would even say that if I take my city, you have basic services. But really, if you have a population of less than 10,000 or if you are in the neighbouring city that has a population of about 6,000, you often have a surgeon but not an anaesthetist or you have an anaesthetist but no surgeon. And that is the reality of a semi-rural region that doesn't have enough people to support all these specialists. Because it's not like when you are close to a big city. But here, you're rural enough that he doesn't come to you're place.

For Francophone women, it appears that even women in urban areas consider themselves remote when speaking of health-care services because they must travel longer distances to obtain services in French (i.e. Greater Vancouver Area, large urban areas). Therefore, the concept of remote in this case is conceptualized by these women in relation to French-language services, as this is their predominant preoccupation. It depends on access to Francophone services, organizations or at a minimum, interactions in French. In the Western provinces, if remote is defined with regard to access to French-language services, most Francophone women are remote, whether they live in urban or rural areas. It is interesting to note as well that in some provinces, a Francophone woman living in a rural community–where Francophones represent a strong majority of the population and where a number of Francophone institutions have been established–is more likely to get services in French than a woman living in an urban area that is predominantly English-speaking. Thus urbanity for Francophone women is not necessarily an advantage if their concern is obtaining services in French and living healthily in French. And rurality can be more advantageous when the Francophone population represents a strong majority or is highly concentrated, but only as regards to basic health-care services, when they are provided. Any specialized health service is provided only in English in most Western provinces, and mostly in English in other provinces to the exception of Quebec.

Rural and remote regions share the same environmental and social benefits with regard to health (fresh air, social support, community involvement, etc.). However, rural and remote communities are further disadvantaged in their access to health-care services because of their geographic distance from major service centers and their low population density.

The remoteness of communities is, according to participants, relative. It largely depends on women's access to transportation (driver's permit; access to a car; available buses and/or trains; cost of flights) and on their needs (childcare, days off from work, etc.) or the difficulty or ease of transportation.

For instance, the Confederation Bridge linking PEI to New Brunswick has certainly made a big difference in facilitating access by limiting travel time and providing more opportunities. Thus women in PEI do not feel as remote as they did when the only way to get off the island was by airplane or ferry. The frequency with which women engage in social interactions, either face to face or over the telephone or the internet, also influences the subjective feeling of remoteness.

Table 12 Responses to the question: Do you think of yourself as a rural woman? As someone who lives rurally or remotely? Both?

Type of community	Total # of participants
Rural	18
Rural and remote	6
Urban	6 (but some as remote with regard to access to services in French)

One distinction some participants made in declaring themselves rural rather than remote was the idea that they did not feel isolated because they were involved in the community, they had access to a vehicle, to the internet, they lived in a Francophone environment…

Moi, je ne me sens pas vraiment éloignée parce que je suis en contact avec du monde partout sur mon ordinateur. Puis je vois du monde et je suis un petit peu partout. Mais s'il y a une femme qui est là-bas, la seule Francophone, souvent les Francophones qui ne demeurent pas dans notre région doivent se sentir beaucoup plus éloignées parce que tes voisins ne sont pas des Francophones. Mais en tout cas, je ne me sens pas vraiment éloignée. C'est juste à cause que je suis beaucoup impliquée. Mais ça peut être différent pour les femmes qui n'ont pas d'auto, qui ont pas de moyen de transport…

I don't really feel remote because I am in contact with people from everywhere on my computer. And I see people and I am a little bit everywhere. But if there is a woman over there, the only Francophone, often the Francophones who don't live in our region must feel much more remote because your neighbours aren't Francophones. But anyways, I don't really feel remote. It's just because I am very involved. But it can be different for women who don't have a car, who don't have transportation…

But if there is a woman over there, the only Francophone, often the Francophones who don't live in our region must feel much more remote because your neighbours aren't Francophones.

Table 13 **Responses to the question: If you could have the undivided attention of key health-decision makers to talk about the state of women's health in your community, what two most important issues would you raise?**

Issues	Examples	Further explanation/detail
Accessibility	Increase number of health-care providers	Allow more foreign physicians and professionals to practice
		Encourage semi-retired physicians to contribute
	Encourage health-care professionals to stay in rural and remote areas	Improve salaries for professionals
	Increase use of nurse practitioners	
	Reduce cost of medication	
	Rotating services to increase accessibility	
	Provide services in rural and remote communities	Create regional service centres
	Provide home visits/services	
	Provide services in French	Proactive services in French
		Improve quality
	Provide transportation	Public transportation or other to allow women to get to the services
Provide financial help to those in need	Stop cutting or reducing social services and programs	Help the poor
Improve the economy and economic conditions	Increase revenues for families, the elderly, single mothers, etc.	
Information/ communication	Inform specialists on the situation of people from remote areas	
	Different agencies should better communicate among themselves to know what services each one provides	
	Women get information through their own organizations, but women not in these organizations do not get the information	
	Promote exchange of information between generations; pass knowledge from elderly to youths	
	Educate women so that they can help their families	Networks of exchange of information

Table 14 Responses to the question: If you could have the undivided attention of key health-decision makers to talk about the state of women's health in your community, what two most important issues would you raise? (continued)

Issues	Examples	Further explanation/detail
Increase services	Increase funding for health-care system	
	Mental health services	
	Home care	Provide services
		Help the caregivers
	Better support for victims of violence, social assistance	
	Health prevention and promotion activities/ services	Create women's health centers across the country
		Services for the family and for early childhood
		Plan for the long term (not short term)
		Maintain/increase specialized prevention services, i.e. speech therapy
		Policies, programs and services to improve lifestyle and culture shift – Prevent burnout; change actual working conditions since people are now overworked (one person doing the job of two or three) – Shorter working weeks to help working parents take care of kids, cook nutritious meals – Diet – Physical activity – School physical education and interscholastic programs – Quit smoking

Table 15 Responses to the question: If you could have the undivided attention of key health-decision makers to talk about the state of women's health in your community, what two most important issues would you raise? (continued)

Issues	Examples	Further explanation/detail
Multidisciplinary health clinics	Centers with integrated health services	To provide services for the person as a "whole"
Inform politicians and decision-makers about the specific realities of women and of Francophones		
Fund and do research on Francophones' health in rural areas	The assessment of the health status is needed to plan and provide adequate services	
Re-evaluate funding priorities	Specialized and expensive services vs. prevention	
Improve women's equity	Financial	Wage equity
		Remunerate stay-at-home mothers, caretakers
		Provide childcare
	Social	Recognize contribution of women's work
	Political	Wanting a stronger voice (corporations and pharmaceutical companies have too much weight) – Make decisions with grass-roots input, from women and from women's groups – Have more women in cabinet to influence decision-making but these women need to be critical of the system, not just reproduce it
Change discourse	From a medicalized discourse focused on disease to a more holistic perspective that includes prevention and alternative health	Provide alternative health services; stop the conflicts between physicians and alternative health providers (i.e. chiropractors)

Participants stressed the need to act now to improve the health-care system. There was a sense of urgency about an impeding health-care crisis (if it did not already exist) and women felt it was important to act now on the Romanow Report and other recommendations.

The two most important issues women raised were obtaining better access to health services and increasing access to and the quality of social and health services. Access meant on the one hand, finding solutions to provide specialized services in the rural and remote community rather than imposing the

problems of travelling on the sick and vulnerable. On the other hand, access also referred to providing better means of transportation when travelling is inevitable.

Le financement, mais je me dis que quand même qu'on serait bien financé, il y a quelque chose aussi où je me dis qu'on paie tous le même montant de taxes, qu'on soit éloigné, rural éloigné ou n'importe quoi. On a droit à nos services sur place. C'est ça que je me dis. On paie les mêmes taxes que les personnes des grandes villes. Pourquoi est-ce qu'on n'a pas droit aux mêmes services que ces grosses villes? Quand tu tombes à 3 000 ou 4 000 personnes de population, je me dis que le gouvernement devrait gérer un peu le programme santé aussi pour qu'on puisse avoir nos services sur place.

Funding, but I say to myself that even though we would be well funded, there is something where we all pay the same amount of taxes, whether we are remote, rural and remote or anything else. We have a right to services where we are. That's what I tell myself. We pay the same taxes as people in the city. Why don't we have the same rights to services as the cities? When you fall to 3,000 or 4,000 people in the population, I say to myself that the government should manage the health system a bit so that we can have our services where we are.

Je pense que c'est plus facile de déplacer un médecin que de déplacer 20 patients qui vont devoir faire cinq, six heures de route pour aller voir le même médecin. Ça serait peut-être beaucoup moins onéreux et puis ça rendrait bien plus service, puisqu'on est en milieu éloigné, que le système prévoit, que les services vont être donnés proches ou à moins de deux heures de route.

I think that it's easier to move one doctor than to move 20 patients who have to travel five, six hours to go see this same doctor. It would probably be a lot cheaper and it would be much more helpful, as when we are far away, the system is set up so that you will have services at least two hours travel time.

Les médecins aussi et les infirmières, tout ce qui touche à la santé, quand ils arrivent ici, ils ne reconnaissent pas leurs diplômes et tout ça. Mais moi, je me dis qu'ils leur paient une formation et puis leur fassent passer tout un examen puis qui les acceptent. Je me dis « on est en pénurie ». C'est quoi là de toujours bloquer et bloquer? Tu as de bons médecins, ceux qui arrivent de l'extérieur [de la province, du pays] seraient prêts à venir travailler ici.

Doctors and also nurses, everyone involved in the health system, when they get here they don't recognize their diplomas and all of that. But I say to myself that they pay for their training and make them pass their exams and they accept. I say to myself, "we've got a shortage". What's the idea of blocking and blocking? You have good doctors, but they come from outside (of the province, of the country) that would be glad to come and work here.

The need for better prevention and for health promotion was also underlined and prioritized by participants. In focusing on prevention, women were also calling for a larger safety net and better socio-economic and working conditions. The latter play a large role in ensuring an improved health status.

Mais il y a de la prévention, puis la prévention de santé à faire. Et si tu regardes où est-ce que l'argent est mis tout de suite, il est pas mis sur la promotion de santé. Puis la promotion de la santé en milieu rural est encore plus importante qu'elle l'est en milieu urbain parce que les gens en milieu rural n'ont pas accès aux services que les gens des milieux urbains ont accès. Donc, je vois que s'il y avait plus d'argent d'investi dans la promotion de santé et la prévention de la maladie, d'ici à 30 ans de sûr, on serait pas dans le pétrin qu'on est. On n'aurait pas à verser autant d'argent pour le système de santé qu'on met actuellement. Puis ça s'empire.

But there is prevention, and health prevention that needs to be done. And if you look at where the money is being put right now, it isn't being put on health promotion. And health promotion is even more important in rural regions than it is in urban regions because people from rural regions don't have access to the services that people in urban regions have access to. So I see that if more money was invested in health promotion and the prevention of disease, in 30 days for sure, we wouldn't be in the mess that we are in. We wouldn't have to put the money we do now in the health system. And it's getting worse.

Moi, je pense qu'il y a un autre aspect qu'il faut que le gouvernement regarde, puis c'est la charge des

travailleurs et des travailleuses. Pas rien que dans le domaine de la santé mais dans tout. Je regarde les coupures qu'on fait dans les institutions d'éducation, de la santé. Les entreprises où on coupe le personnel. Alors, les personnes qui restent font le boulot de trois personnes parce (…) qu'on n'a pas réduit l'output. On avait huit employés puis on est rendu à trois, puis on est supposé produire autant, si pas plus. Plus avec moins. Mais moi, je pense que quand même, il y a énormément de stress dans le domaine du travail des gens. Et puis ça, ça affecte la santé. Il y a plus de journées de maladie de prises. Il y a plus de burnouts et puis c'est quelque chose qu'on a de la misère à reconnaître. C'est que souvent les gens se font laisser aller avant qu'ils puissent embarquer sur les plans de santé qu'ils ont payé parce qu'on interprète d'une différente façon et puis après ça, nos gens sont…

I think that another aspect that the government needs to look at is the workload of the employees, not only in the health sector, but in everything.

I think that another aspect that the government needs to look at is the workload of the employees, not only in the health sector, but in everything. I look at all the budget cuts done in educational institutions, in health, in the businesses where they fire people. So the people left behind do the job of three persons because… we haven't reduced the output. We had eight employees and now we are three and we are supposed to produce as much if not more; more with less. But I still think that there is lots of stress in people's work. And that affects health. More sick-leave days are taken. More burnouts and it's something we have trouble recognizing. It is often the case that people are laid off before they can join the health plans that they have paid because it was interpreted in a different way ant that, our people have…

Improve the quality of care available in rural and remote areas.

On n'a pas le choix des spécialistes. S'il y en a un qui décide, je ne sais pas comment c'est arrangé au Collège des médecins, mais s'il y en a un spécialiste qui vient en région, bien c'est lui qu'il faut aller voir. Si on veut en voir un autre, c'est nous autres qu'il faut qu'on y aille. Et puis souvent, ils sont obligés d'en faire de la région. Je pense qu'à un moment donné, au niveau de la loi, quand ils sortent de l'école des médecins, ils sont obligés. Ils ne sont pas toujours intéressés, ces médecins-là, à nous servir.

We don't have the choice for specialists. If one of them decides, I don't know how it's organized at the CMA, but if a specialist comes to our region, it's him we have to see. If we want to see another one, we have to travel to him. And often, they're obligated to practise in remote regions. I think that at a given time, the law gives new doctors the obligation. These doctors aren't always interested in serving us.

Provide a voice for women in decision-making processes since women are concerned about these issues and they in fact have much knowledge and experience since they are the professional healthcare providers and the caretakers as well. Women are pushing for a change in the discourse of health so that a more holistic perspective will be encouraged and alternatives to simply focusing on the treatment of disease will be provided.

C'est un peu inquiétant—et je sais que je sors du sujet—mais c'est un peu inquiétant ce qui se passe présentement parce que les études qui sortent dans la francophonie, c'est toujours le même modèle. Puis nous autres, on est toujours à la traîne en arrière, en train de dire non, c'est pas ça qu'on veut. C'est que les femmes, c'est elles non seulement qui utilisent les services mais on travaille dans le milieu et puis on n'a pas de crédibilité dans ce qu'on dit et puis c'est inquiétant parce qu'on va être encore en train d'essayer de défaire ce qui va être mis en place, si on n'a pas notre place.

It's a bit worrisome, and I know I'm getting off topic, but it's a bit worrisome with what is going on now, because students who leave the Francophone community always follow the

same model. And we are always lagging behind, saying no, that's not what we want. Women, it's them that use and work in the health services field, but we aren't credible in what we say and it's worrisome because again, we'll have to undo what is being set up if we don't have our place.

Je pense qu'il y a encore un problème. Ils ne comprennent pas, mais ils pensent qu'un groupe de femmes représente seulement les femmes et ne réalisent pas que les décisions qui sont prises, qui affectent les femmes affectent la société au complet. Je pense qu'il y a encore cette image-là de libéralisme féministe et ils ne réalisent pas jusqu'à quel point que l'impact des décisions des opinions des femmes affecte la société au complet, la famille, leur conjoint, l'éducation—ça affecte absolument tout. Et je pense qu'ils ne comprennent pas encore ça. Je ne sais pas ce que ça prend, mais ils ne comprennent pas. Ça fait que c'est vraiment vu comme une perspective d'un groupe cible et puis pourquoi prendre ces décisions pour représenter la communauté au complet.

Moi, je suis tannée qu'on se fasse voir comme un interest group. Viens pas me dire que Bombardier n'est pas un interest group! Ne viens pas me dire que Ipsco est pas un interest group. C'est vraiment… C'est pareil comme si à cause qu'on est des femmes ou qu'on est un groupe de Francophones, on est un interest group puis on est des sangsuces. On suce juste le sang de la société et on ne contribue pas, et que c'est vraiment l'inverse.

I think that there is still a problem. They don't understand, but they think that a women's group only represents women and do not realize that the decisions that are taken, that affect women affect the whole society. I think that there is still this image of liberal feminism and they don't realize to what point the impact of the decisions of women's opinions affect the whole society, family, husbands, education, it has an effect on absolutely everything. And I think that they still don't understand this. I don't know what it takes, but they still don't understand. So it's still seen as the perspective of an interest group and why take decisions that will represent all of the community.

I am tired of being perceived as an interest group. Don't tell me that Bombardier isn't an interest group! Don't tell me that Ipsco isn't an interest group. It's really… It's as if because we are women or that we are a group of Francophones, that we are an interest group and bloodsuckers. We only suck the blood of society and do not contribute, and it's really the opposite.

Puis surtout en milieu rural, ces femmes ont encore moins de voix. Les communautés sont petites. On le voit. Ce que tu disais pour ce qui était dans les situations où il y a de l'abus, les femmes ne veulent pas parler. Bien, c'est la même chose. Quand les femmes sont dans des couples exogames ou tout simplement dans une petite communauté, elles n'iront pas revendiquer rien en français. On va se faire pointer du doigt. Être Francophone minoritaire, ça veut pas dire qu'on est des activistes puis qu'on est des militantes. Puis déjà d'être féministes, on se fait pointer du doigt. S'il faut qu'on aille au bureau de poste en plus puis commencer à demander un service en français…

And especially in rural areas, these women have even less voice. Communities are small. We see it. What you were saying about women in abuse situations, women don't want to talk. Well, it's the same thing. When women are in exogamous relationships or simply from a small community, they won't advocate for nothing in French. We'll be finger pointed. To be Francophone and minority, doesn't mean that we are advocates and lobbyists. And already to be feminists, we get finger pointed. If on top of that we have to go to the post office and ask for services in French….

Table 16 Responses to the question: How satisfied are you with the quality of health and health care for women and girls in your area?

Level of satisfaction	Examples	Further explanation/detail
Satisfied	Fairly easy to get an appointment with local doctor (if one has a family doctor!)	
	Information provided in the community	
	Health professionals are sometimes more dedicated, they know the people	
	Introduction of nurse practitioners where they do exist has been a good improvement	
	Health status has generally improved	
	Basic services and information available	
	More services and programs are now available in some rural areas (rather than having to travel to larger centre)	Mobile mammography services
Not satisfied	Lack of services and lack of quality of existing services	Seniors
		Information
		Lack of services, never mind the quality!
		Younger generations are leaving the rural and remote communities partly due to the lack of quality in the services
		Services in French are inexistent or not of good quality
		Errors in making diagnostics
		Mental health
	Lack of health-care professionals	Burnout among health-care professionals
		No access to a family doctor
		Introduction of nurse practitioners means physicians come even less
		Health professionals positions not filled
		Specialist and professionals are too busy
	Not enough financial support	Of Francophone groups
		To ensure services in French
	Waiting lists	
	Lack of prevention services and resources	Diet, exercising, smoking
	Specific health problems on the rise	Obesity

Healthcare providers are too busy and do what they can with what they have (to provide good services) but it is not enough.

Ça fait que quant au service de santé, bien, moi, je trouve qu'on fait du mieux qu'on peut avec les ressources qu'on a. Mais on ne donne certainement pas des soins de santé qui sont Cadillac, bien loin de là. (…) Je regarde, on travaille et on a une pleine charge de patients puis j'ai six infirmières sur la route à chaque jour. J'ai du travail pour sept à huit infirmières. J'ai des filles qui sont en train de se brûler parce qu'on n'a pas suffisamment de ressources. J'ai une ergothérapeute qui a 60 patients. Imaginez-vous avoir 60 patients à desservir dans des maisons et les écoles.

It means that for health services, well, I think we do the best we can with the resources we have. But we certainly don't give Cadillac health services, very far from that … I look, we work and have a full load of patients and I have six nurses on the road each day. I have work for seven to eight nurses. I have women that are burning themselves out because we don't have enough resources. I have an occupational therapist with 60 patients. Imagine having 60 patients to care for in houses and schools.

Table 17 **Responses to the question: Do you think the quality of health care for women in your area has changed in the past two years? In the past five years? For better or worse? Please give examples.**

Level of satisfaction	Examples
For better	More programs targeting women (i.e. mammography)
	More clinics and information (i.e. sexual education)
	More services (new machines/technology for diagnostic purposes; nurse practitioners)
	New Francophone health centers
	Some people are adopting healthier behaviours (stopped smoking, better diet…)
For worse	Lack of prevention (Dealing with problems too late)
	More informed but behaviors are not changing (exercise, diet, smoking…)
	Less health-care providers
	Funding cuts, less services (what used to be regional services are now provincial services and no longer anonymous, i.e. telephone info line; reduction of services in French; cuts in physiotherapy services)
	Lack of Francophones or bilingual health-care providers
	With an aging population, there is a need for increased services
	Waiting lists

The creation of Francophone or community-health centers has been identified by participants in some regions as an improvement in the provision of health services.

L'accessibilité disons pour le moment aux soins de santé, en ayant le centre de santé même dans la région, dans le local. Et puis ce qui rassure beaucoup les femmes c'est que nous avons une infirmière et un infirmier praticien sur place continuellement. Aussi, il y a des activités qu'on fait et puis il y a une infirmière qui vient prendre la pression des personnes et ça rassure beaucoup, beaucoup les femmes. Nous autres, c'est plus les femmes. Moi, je travaille avec les personnes âgées plus et puis c'est ça pour le moment qui s'est amélioré dans notre patelin, disons.

Accessibility for the moment to health services, by having the health centre in the same region, in the community. And what really reassures people is that we continually have a nurse practitioner on site. Also, there are activities that we do and there is a nurse that comes to take people's blood pressure, and that reassures

many, many women. Us, it's not just women. I work more with elderly people and that's why it has gotten better in our community

While women recognized some gains in providing new models of health-care services and more information about specific women's health issues, it seemed that they also were discouraged to notice a decline in services.

Research Agenda

How would you define "your community"? Are there women's health issues about which you think more information is needed in order to prompt appropriate action in your community or region?

Table 18 Responses to the question: How would you define "your community"?

Type of community	Examples
Geographic community	Neighborhood
	Village
	Town
	Region/County
Cultural/linguistic community	Acadian (provincial or local/regional)
	Francophone (provincial or local/regional or Prairie Francophone community)
Interests	Kids' Soccer
	Work
	Women's community
Commitment/ties	Family
Religious	Parish

The most spontaneous answers of most participants referred to the geographic community (which is sometimes the same as the parish in case of villages), the Francophone community and family.

Why is that with all the information, all the knowledge that we have let's say on smoking, why in a rural area is the number of people, or women that smoke continue to increase, especially amongst young women? Why?

Table 19 Responses to the question: To put it another way, have you ever felt concerned or curious about some aspect of women's health care in your area and wished that someone would look into it further?

Type of question	Examples
To better provide services	Why, despite all recent information are people not changing lifestyle and behaviors (diet, smoking…)?
	What to do to encourage/help them lead healthier lives?
	Find more creative ways to provide services to rural and remote communities
	How to better reach women and provide them with the information? (Especially those women that are not currently involved)
	Home care and how informed/competent are we as caretakers. More research on our roles as caretakers.
Health problems	Menopause and hormones; Impact of contraceptive pill
	Nutrition (adapted to special circumstances)
	Vitamins
	Cancer (why more in rural areas); Cancers particular to women (i.e. breast)
	Impact of environment on health (i.e. salt on roads, water and air pollution; i.e. allergies, asthma)
	Cardiovascular disease in women
	Impact of medication
	Genetic conditions among populations (i.e. Acadians)
	Effects of recreational drugs and alcohol
	Mental health (women, adolescents)
	Weight gain and obesity
	Alternative medicine
	Bulimia and anorexia
	Post-partum depression
Social and economic factors	Ageism and Access to Services
	Diverse realities of women (age, socio-economic status…)
	Child poverty
	Isolation (how it is experienced by women and its impact on health)
	Impact of language on health and health care (when you can't get the services in your language or first language)
Comparative	Women/men
	Health of population in rural communities with many health services compared to that of other rural communities with less services

This was not an issue participants had thought about much before this interview. It appeared that women working as health-care providers or involved as volunteers in the social and health service field had more spontaneous ideas about research needs. And for these women, research topics focused on how to change behaviours and better serve people as opposed to finding cures or gaining more knowledge about specific diseases or health problems.

Pourquoi est-ce que malgré tout l'information, toutes les connaissances qu'on a disons sur le tabagisme, pourquoi est-ce que peut-être dans le milieu rural, le taux des gens, des femmes qui fument continue à augmenter, surtout parmi les jeunes femmes? Pourquoi? Vous avez l'information. Vous savez. C'est quoi qui vous empêche d'arrêter de fumer ou de changer vos habitudes? (…)

Peut-être se pencher sur tout ça.

Pourquoi vous changez pas vos habitudes alimentaires? Pourquoi vous changez pas vos habitudes d'activité physique?

Le comportement, comment changer les habitudes de vie, c'est plus ça qu'il faudrait étudier, plus que OK, on sait que c'est pas bon pour vous à cause de ça, ça, ça, et ça.

Why is that with all the information, all the knowledge that we have let's say on smoking, why in a rural area is the number of people, of women that smoke continue to increase, especially amongst young women? Why? You have the information. You know. What is stopping you form stopping to smoke or from changing your habits? …

Why aren't you changing your nutritional habits? Why aren't you changing your physical activity habits?

The behaviour, how to change life styles, that's what we would need to study, we know that it's not good for you because of this, this, this and this.

Table 20 **Responses to the question: The Centres of Excellence do research that involves community members from the start. Do you have any suggestions on how to improve this model?**

Concern with duplication of research studies
Applied research: Research should be "used" or about "usable" topics
Action research, involve women, women groups and communities
Produce reports, documents, books women can read and use; provide concrete outcomes of research
Gather data from more women
Collect data in rural areas
Women's Health Centres of Excellence should provide documentation and services in French
Include Francophone women
Include a greater diversity of women (women not in associations, less privileged women)
Continue with data collection activities that foster interaction
Interviews and focus groups rather than questionnaires
Raising awareness of women through research and such interactions

Some participants stressed the idea of producing applied research that will be useful to women in the communities; to health-care providers in the rural communities.

Moi, j'aurais tendance à faire une recherche appliquée. Ça veut dire que j'aurais tendance à proposer un genre de projet pilote qui aurait comme objectif ce que moi j'ai proposé, mais c'est sûr que beaucoup de gens seraient d'accord avec ça, ce qui est prévention, éducation populaire, échange entre les générations et tout ça, prendre une communauté et se dire dans cette communauté-là, on va appliquer cette approche-là. On va faire de la prévention, on va faire de l'éducation populaire, on va essayer de créer des échanges entre les générations pour que les expériences se transmettent. On va essayer d'impliquer cette façon de travailler plus sur l'individu que sur le système. Et dans une communauté assez particulière.

I would have a tendency to do applied research. That means that I would tend to propose a kind of pilot project that would have as an objective what I have proposed, but I am sure that lots of people would agree with that, which is prevention, popular education, inter-generational exchanges and all of that, take a community and say in that community, we will apply this

approach. We will do prevention, we will do popular education, we will try to create intergenerational exchanges so that experience can be transmitted. We will try to involve this kind of work more on the individual than on the system. And in a particular community.

Participants profited from the interactive process of the data collection and mentioned that it was more rewarding for them as they felt they could contribute more effectively, but also gain more out of participating in the discussion and hearing other women's opinions. They also felt that a limited number of women were being consulted and that Francophone participants were women involved in their communities. They thus expressed a need for larger consultations with a greater diversity of women.

Il y a aussi, quand les gens, il y a des consultations qui sont faites, je pense que ça suscite en groupe la question d'une ou la réponse d'une va susciter : « ah tiens, oui, j'avais pas pensé à ça. » Mais il y a ça aussi. Ça fait que ça crée automatiquement une sensibilisation dans la communauté. Quand il y a des sondages sur place avec pas seulement les pourvoyeurs de services—si je peux les appeler de même—mais les personnes qui reçoivent ou les usagères. Et je pense que c'est là parce que je me rends compte à cause de comités où je siège qu'on n'a pas du tout la même interprétation de la santé ou les besoins des personnes selon qu'on est un pourvoyeur de santé ou une usagère. Ça, je pense qu'en tout temps, si on veut avoir quelque chose qui est représentatif, il faut que tu aies les deux groupes assis à la même table et puis il ne faut pas qu'il y ait un groupe qui soit beaucoup plus…

There is also the fact that when people, when group consultations are done, I think that that encourages the question of one person or the response of another will encourage: « yes, I hadn't thought about that. » But there is also that. It automatically creates consciousness raising in the community. When there are local surveys but not only with service providers if I can call them that, but also with the people who are receiving or the users. And I think that it's there because I am realizing that because of committees where I sit that we don't all interpret health in the same way or people's needs whether we are a health provider or a user. That, I think at all time, if we want something that is representative, you have to have both groups sitting at the same table and they have to be about the same size…

J'ai l'impression d'avoir contribué plus efficacement que de remplir nos petits questionnaires puis le mettre à la poste.

I have the impression of having more efficiently contributed than if I had filled out a mail survey and then sent it.

General Comments

1) Women's health issues vs. health issues in rural and remote areas vs. Francophone health issues

What emerged from the discussion with the minority Francophone women living in predominantly Anglophone communities was that the remote (rather than rural) and Francophone issues with regards to health and health-care services were more of a concern for these women than specific women's health issues. They were concerned with problems of constrained and limited access to a variety (not just biomedical) of quality health-care services because of geographic distance and low population levels. This problem seemed so fundamental for the overall population in rural and remote areas that the women were not particularly preoccupied with specific women's health issues. The second issue that arose as highly important was access to quality health-care services in French. As if concerns about women's health can come to the forefront only once so-called basic health concerns are resolved. As if thinking about specific "women's health" problems is a luxury in remote areas.

Il y a aussi une rotation qui se fait. Alors, il n'y a pas toujours un médecin de disponible, ou le médecin qui parle français, bien, c'est pas son tour. La même chose pour les infirmiers et les infirmières. Et ça, c'est tant à l'urbain qu'au rural. C'est très, très difficile d'accéder aux services en français. Puis s'il y a un médecin Francophone, il est tout de suite surchargé. Sa besogne devient presque intolérable. Alors, il y en a qui laissent. Il y en a qui quittent.

There is also a rotation that is done. There is not always a doctor available or it's not the doctor who speaks French's turn. It's the same thing for nurses. And that is as much urban as rural. It is very difficult to access French services. And if there is a Francophone doctor, he is right away overworked. His workload almost becomes unbearable. So some of them quit. There are some that leave us.

Sauf que moi, je suis en région urbaine. Et j'aurais probablement un meilleur service en français dans le village que j'en aurais en ville, ici. Je sais que si je vais à l'hôpital, dans le village, les chances sont que je pourrais avoir une infirmière qui parle français, tandis qu'en ville, c'est une autre histoire. Si on regarde du côté Francophone, c'est complètement différent. Je dirais que c'est l'inverse de ce que c'est normalement.

Except that I'm in the urban region. And I would probably have a better service in French in the village than I would have in the city, here. I know that if I go to the hospital, in the village, chances are that I will get a nurse that speaks French, while in the city, it's another story. If we look at the Francophone side, it's completely different. I would say that it's the opposite of what things normally are.

Si tu demandes je veux parler en français, est-ce que vous parlez français? Ah non, excuse-moi, une minute. Là, elle te met de la musique. Et tu écoutes un beau concerto de je ne sais pas quoi, là. Bien moi, je te dirais que ça me choque, ça. Je ferme la ligne parce que quand je veux écouter de la musique, je ne téléphone pas. J'ouvre la radio.

Quand j'appelle, moi, c'est pour parler à quelqu'un. Puis ça, je comprends que c'est moins dispendieux qu'un employé, mais appuyez sur 1 pour le service, appuyez sur 2 pour tel autre et puis le service en français. Là, tu appelles au service en français et ils veulent savoir quel département. Encore, c'est une boîte vocale. Et puis là, ils te font attendre. Tu es en attente continuelle. Et là, ne quittez pas pour garder ta priorité d'appel.

Votre appel est important pour nous.

On la sait, cette petite chanson-là. L'autre jour, j'ai attendu 17 minutes. J'ai rappelé et là, j'ai réussi à parler en anglais. Et là, j'ai dit je veux un service en français, dans la même heure, s'il vous plaît…

Oui, mais ton personnel français, quand tu es obligé d'aller le chercher à l'autre bout de l'hôpital, il faut que tu attendes.

Ceux qui parlent anglais et qui disent ah bien, laisse faire. J'attendrai pas une heure, je vais te parler en anglais. Ça, ça fait-tu plaisir aux Anglophones, ça, hein. Moi, ça me fâche, ça. Ah, vous l'avez le service français. On n'a pas à se plaindre, on l'a le service français. Mais ne regarde pas la qualité du service français qu'on a, là.

They were concerned with problems of constrained and limited access to a variety of quality health-care services because of geographic distance and low population levels.

If you ask I want to speak French, do you speak French? Oh no, wait a minute. And then they put music on for you. And you listen to a nice concerto of I don't know what. Well, I would tell you that that makes me mad. I hang up because when I want to listen to music, I don't call. I turn on the radio. When I call, it's to talk to someone. And I understand that that is cheaper than an employee, but press on 1 for service on 2 for something else and for service in French. Then you call the French-language service and they want to know which department. Again it's a voice box. And they make you wait. You are continually waiting. And then, don't hang up to keep your priority.

Your call is important to us.

We know that little song. The other day I waited 17 minutes. I called back and then, I was able to

speak in English. So I said I want service in French, during the same hour, please….

Yes, but your Francophone personnel, when you have to go get it at the other end of the hospital, you have to wait.

Those that speak English and who say, well forget it. I'm not going to wait an hour, I can talk to you in English. That really pleases the Anglophones. That makes me mad. Oh, you have the French language services. We shouldn't complain, we have the service in French. But don't look at the quality of French service that we have.

Puis il faut pas oublier la confidentialité parce que quand on demande à une autre personne de traduire pour nous autres, il y a toute la dignité du client. Puis ça souvent, c'est pas pris en considération. Moi, j'ai vu des cas où ils appelaient le concierge parce que c'était le seul Francophone qu'ils connaissaient pour venir faire de la traduction. Moi, j'appelle pas ça un service de qualité. J'appelle pas ça un accès, le même niveau d'accès que les Anglophones peuvent avoir.

We can't forget confidentiality because when we ask another person to translate for us, there is the whole question of the patient's dignity. And that is often not taken into consideration. I have seen cases where they would call in the janitor because he was the only Francophone that they knew to come and do the translation. I don't call that a quality service. I don't call that access, not the same level of access as Anglophones can have.

This did not appear to be the case for women living in rural (without being remote) areas since the distance to specialized and a variety of health-care services was not as great.

For the women living in predominantly Francophone areas, the issue of language did not emerge during the discussion until I raised it at the end of the interview. When prompted on this discrepancy between their answers and those of women living in Anglophone areas, they answered that it was a given for them that health services should, and would, be in French. They had not mentioned it because French-language services were available in their community. They did underline that for other women in other regions of their respective provinces, health-care services were not available in French and that it was a major problem.

The specificity of women's health issues did emerge more spontaneously with these women who lived in rural (but not remote) areas and felt that services in French were available to them because of their proximity to large centers. The rural and remote women living in predominantly Francophone villages felt that in terms of basic needs, they were well served with a variety of health-care services in French in their own remote community, which according to them was an exception. But, in some provinces, they did not have any access whatsoever to French-language specialized services.

Au départ, nous autres, on a un hôpital, puis je peux te dire qu'on a beaucoup de difficulté avec le français. Tout de suite en rentrant, on en a une qui n'est même pas bilingue à l'entrée, à la réception. (…) Mais tout de suite là au départ, c'est une barrière, la langue, tout de suite là. Ça refroidit un malade, ça, qui rentre et qui n'est pas capable de dire qu'est-ce qu'il veut dire. Puis ce n'est pas qu'on ne se bat pas pour ça, mais [maintenant] quand on est malade on est content parce que c'est une française qui est [à la réception]. [La réceptioniste qui ne parle pas français] a eu un bébé et elle a pris son année [de congé]. Aie, imagine-toi que le monde était content d'avoir une française au bureau en rentrant, à la réception. Je trouve ça dommage. Et puis tout de suite là, tu as une barrière là qui est vraiment. (…) Oui, et puis quand tu es souffrant et puis que tu es obligée d'aller courir pour un interprète ou qu'il faut qu'il aille à l'autre bout de l'hôpital pour chercher une garde pour t'interpréter, bien durant ce temps-là, c'est toi qui pâtis. J'en ai fait l'expérience, ça fait que je peux te le dire.

To begin with, we have a hospital, but I can tell you that we have lots of difficulty with French. Right when you come in, we have one that is not even bilingual at the entrance. … But right from the start, that is a barrier, the language,

right away. That cools down a sick person that is coming in and that isn't able to say what he wants to say. It's not that we don't fight for that, but (now), when we are sick we are happy because it's a Francophone that is (at the entrance). (The secretary that doesn't speak French) has given birth and has taken a year's (leave). Hey, imagine that people were glad to have a Francophone at the entrance. I find it too bad. And right there, you have a barrier that is really…. Yes, and when you are suffering and that you have to run around for someone to translate or that you have to go to the other end of the hospital to find a nurse that can translate, well, during that time, you're the one that is suffering. I have experienced that, so I know what I am talking about.

2) Health as an individual responsibility vs. the impact of the determinants of health (biological, environmental, social…)

One interesting paradox throughout the responses is the concurrent articulation of two different ideas about health. On the one hand, participants expressed much concern over individual behaviors (diet, smoking, sedentary lifestyle…) and individuals' responsibility for their own health. But on the other hand, women also stressed the socio-economic and the biological determinants that impact one's health. They manifested an awareness that health is not merely determined by one's choices and practices, but also by larger social and institutional conditions. Women in focus groups articulated an understanding of health that presumes a complex interaction between *invididual*, *family* and *community* behaviours, practices, values and culture and the determinants of health (social, environmental, biological…). Some action can be taken on these (i.e. social, environment) while others appear to be "inevitable" (but perhaps "controllable" (i.e. biological determinants).

Themes that arose regarding individual, family and community responsibility for health: nutrition/diet, physical activity, smoking…

Themes that emerged regarding the determinants of health: socio-political (economy, gender equity, values and culture… [government responsibility: underfunding of health system; need to focus on prevention and promotion of health…) and environment (industrial pollution)

3) Importance of prevention and promotion in fostering a long-term plan for healthcare services as opposed to focusing on disease and immediate health issues.

This concern for a stronger focus on prevention and promotion intersected the two above concerns for individuals' responsibility for their own health as well as the non-behavioral health determinants.

However, this concern for prevention was also manifested through criticisms of the current hegemonic medicalized health discourse focused on treating disease and the call for a more holistic perspective of health,

based on prevention and inclusive of alternative health practices and services. Women repeatedly mentioned the need for a shift towards treating the individual as a whole person, and not strictly focusing on isolated health issues/problems.

On a fait notre AGA de l'année passée, on a fait un atelier santé et ce que les femmes disaient. C'est qu'elles dénoncent le fait que justement, c'est un modèle médical partout qui leur est offert et quand elles demandent un service plus holistique, qu'elles soient traitées comme un tout, ça passe pas. Donc, si elles découvrent la perle qui va le faire, elle serait peut-être prête à faire des distances, je suppose pour ça. C'est ce qu'on essaie, nous autres, de promouvoir au sein de nos organismes puis c'est pour ça qu'on veut être autour des tables. C'est pour le dire et pour que ce soit reconnu.

We had our AGM last year, and we had a health workshop and what the women were saying is that what outrages them is that it is a medical model that is offered to them wherever they go and that when they ask for a more holistic service, that they be treated as a whole, that doesn't go over. So, if they discover the gem that will do it, they will probably travel long distances for that. That is what we try to promote amongst our organizations, and that is why we want to be sitting at the table. It's to say it and so that it can be recognized.

Mais je pense aussi qu'il faut éduquer les médecins à utiliser des soins de santé qui sont autres que les services à pilules.

But I think that we have to educate doctors to use health services that are other than pill services.

Moi, je leur dirais, je leur demanderais et leur dirais de cesser d'investir de l'argent, d'écouter les compagnies pharmaceutiques, d'écouter les faiseurs de machines super sophistiquées puis de justement d'aller du côté de la prévention. Mais aussi de voir, de cesser de traiter le bobo pour le bobo, mais de voir la personne justement d'une approche holistique, de voir que la personne, c'est un tout et puis de commencer de ce côté-là. Puis en faisant de la prévention par rapport à la santé de la personne, la santé sociale aussi, que d'investir dans le social puis d'investir dans les structures qui font que les communautés sont solides, sont en santé et que les individus qui sont dans ces communautés-là vont être en santé. Qu'on cesse d'écouter tout le lobby de pilules et puis de machines, on verrait une grosse différence.

I would tell them, I would ask them and would tell them to stop investing money, to stop listening to pharmaceutical companies, to very sophisticated machine builders and to start to go towards prevention. But also to see, to stop treating the ailment for the ailment, but to see the person in a holistic fashion, to see that the person is a whole and to start on that side. And to start doing prevention for the person's health, social health too, investing in the social and then investing in structures that make the communities strong and healthy so that the individuals in those communities will be healthy. If we stop listening to the pill and large machinery lobby, we would see a big difference.

C'est aussi bien qu'il fasse des centres de femmes partout au pays.

Des centres de santé familiale ou des centres de femmes où les personnes peuvent aller et d'avoir accès à une multitude de professionnels qui travaillent sous le même toit, je pense que ça pourrait certainement pas faire tort plutôt que d'être obligé de s'en aller et de visiter silo par silo. On traite pas la famille dans son ensemble, là. Ils sont pas rendus là encore.

It would be better to set up women's centres all across the country.

Family health centres or women's centres where people could go and have access to various professionals who work at the same place. I think that that would be better than having to go visit from silo to silo. We don't treat the family as a whole. They aren't there yet.

Some also claimed that the current health system (if not social system) fosters dependence on professionals and that it is important that women re-appropriate their own health practices, and make their own health decisions.

Mais je trouve que ce n'est pas fou de parler de ça, dans notre monde d'aujourd'hui, c'est les systèmes aussi qui veulent ça, on nous rend de plus en plus dépendant de systèmes, que ce soit le système de santé et autres. Un système de production, par exemple. En ville, on est totalement autonome dans le système de production. Alors moi, je pense que la santé des femmes dans le milieu éloigné,

moins elle doit être autonome de ces systèmes-là, plus elles vont être solides. C'est sûr que des femmes qui vivent dans des milieux éloignés depuis des générations en génération et qui ont conservé ces habitudes de production autour d'elles de santé de suivre sa santé, être capable de faire les accouchements, par exemple, s'il y a des urgences, être capable de soigner les enfants, les femmes qui possèdent ça. Moi, je fais partie des groupes de sages-femmes très anciens. Maintenant, je ne le fais plus parce que maintenant, on se dit récupéré par le système de la santé, mais j'ai déjà fait partie des groupes de sages-femmes. Et moi, faire partie d'un groupe de sages-femmes quand j'étais toute jeune et que j'avais mes premiers enfants, ça m'a redonné ce que moi j'appelle le pouvoir de ma santé.

But I think that it's not crazy to talk about that, in our world today, it's the systems that want that, they make us more and more dependent on systems, whether it be the health system or others. A production system, for example. In the city, we are totally autonomous in a production system. So I think that women's health in a remote area, the less they are autonomous of those systems, the more they will be solid. It is certain that women who have lived in remote regions from generation to generation and that have kept the habits of producing around themselves of health, of following their health, of being able to attend births for example, if there is an emergency, to be able to care for the children, the women who possess that. I am part of the very old groups of midwives. I no longer do it since we say it was "recuperated" by the health system, but I was once part of a midwifery group. Being part of this group of midwives when I was young and that I had my first children gave me what I call power over my own health.

Et moi, je pense que rendu à un certain âge, que ce soit rural ou pas, le système maintient les personnes pour qu'elles soient toujours accrochées à des médicaments. Quand tu vas voir un médecin—moi, j'y vais souvent, j'y vais très souvent—et à chaque fois que tu vas voir le médecin, il rajoute une pilule. Il en enlève une et il en rajoute une. Tu dis « coudons, là ». Je regarde juste mon mari. Il a 61 ans. Je veux bien croire qu'il est cardiaque. Il a 13 pilules le matin, toutes en ligne, et il les prend.

And I think that at a certain age, whether it be rural or not, the system keeps people so that they will always be dependent on medication. When you go see a doctor, I go often, I go very often, and every time that you go see the doctor, he adds a pill. He takes one away and adds another. You say, "well". I just look at my husband. He is 61 years old. I agree that he has a heart condition. He takes 13 pills in the morning, all in a row and he takes them.

4) Recognition that we did not talk about particular issues of at-risk populations.

As a final comment, at the end of the focus groups and interviews, participants recognized that they had not specifically discussed issues concerning particular at-risk populations such as the homeless, sex workers, victims of family and/or sexual abuse/violence, seasonal workers (i.e. on fruit farms in the summer) and the destitute. Although issues of poverty did concern their communities, they did not have much close hand experience with those living in poverty. They expressed concern and identified groups that need help and better policies and programs, but there were no suggestions or detailed discussion of what these policies and programs would entail.

Endnotes

1. With thanks to Ivy Bourgeault , PhD for portions of the Introduction and Methods sections.

Appendix D
Demographic Survey

Rural and Remote Women's Health Focus Group Demographic Survey

Thank you for agreeing to participate in this joint research project involving Centres of Excellence for Research in Women's Health in four regions of Canada. This research has been funded by the Women's Health Bureau of Health Canada. The research in this project is being administered by the National Network on Environments and Women's Health (NNEWH), based at York University in Toronto. Dr. Suzanne MacDonald and Marilou McPhedran are responsible for this study at York University. You can reach Marilou at marilou@yorku.ca or by phoning 1 416 736 5941 if you have any questions or concerns. Collect calls will be accepted if you mention that you are a focus group participant.

Before we begin today's focus group discussion, we are asking you to take a few moments to write your answers to the short survey in the space provided below. You will not be identified in the report on the results of this focus group. Information from this survey will be used to produce a summary profile of focus group participants in different parts of Canada, without any individual being identified. Completion of this survey is voluntary. You may refuse to answer any specific questions on the survey. Please place your completed survey back in the unmarked envelope and put it into the box near the focus group facilitator. If you do not wish to complete this survey, please place the blank survey form back in its envelope and place it in the box. Thank you very much!

Questions

1. How old are you?
   ❑ 16-25 ❑ 26-35 ❑ 36-45 ❑ 46-55 ❑ 56-65 ❑ 65+

2. What level of schooling did you complete? _____

3. Is your personal annual income, after taxes:
   ❑ $15,000 – 24,999 ❑ $25,000 – 34,999 ❑ $35,000 – 44,999 ❑ Above $45 000

4. What is your occupation? _____

5. What is the approximate population of your community in the rural or remote area where you live? _____

6. What is your present marital status?
   ❑ Single ❑ Married ❑ Unmarried and living with partner
   ❑ Separated ❑ Divorced ❑ Widowed

7. If you have children, what are their ages? _____

8. a) Do you live in the same geographic area as where you work? _____

   b) How many miles one way do you have to travel to work? _____

9. If different from where you live, what is the approximate population of where you work? _____

10. Approximately how far/how long do you (or your clients/ the women you represent) have to travel to reach the closest:

nurse?	distance _____	travel time _____	don't know _____
nurse-practitioner?	distance _____	travel time _____	don't know _____
physician?	distance _____	travel time _____	don't know _____
specialist?	distance _____	travel time _____	don't know _____
alternative health care provider?	distance _____	travel time _____	don't know _____

Appendix E

Focus Group Interview Guide

- *Health*
  - What are the things, such as assets/resources/services that promote your health/the health of your clients? (Facilitator may need to prompt people here to think broadly beyond physical health and health care, e.g. spirituality, economics, workplace issues, division of labour; mental health, threats of violence, environmental concerns etc.)
  - What are things, such as barriers/attitudes/rules/lack of services that threaten your health/the health of your clients?
- *Rurality*
  - When you think of rural and/or of living remotely, what comes to mind?
  - Do you think of yourself as a rural woman? As someone who lives rurally or remotely? Both?
  - What makes your life rural and/or remote?
  - In what specific ways does living rurally or remotely affect your health or the health of those in your care? (e.g. geographic dispersion of services, income, employment conditions, access to education, social expectations and attitudes, weather/seasonality, degree of social support, quality of social relationships, housing, recreation etc.)
- *Policy Framework:*
  - "If you could have the undivided attention of key health-decision makers to talk about the state of women's health in your community, what issues would you raise?"
  - "If you could change two things to promote better health of women in your community, what would they be?"
  - "How satisfied are you with the quality of health and health care for women and girls in your area?"
  - "Do you think the quality of health care for women in your area has changed in the past two years? In the past five years? For better or worse? Please give examples.
- *Research Agenda:*
  - "How would you define "your community"? Are there women's health issues about which you think more information is needed in order to prompt appropriate action in your community or region?"
  - "To put it another way, have you ever felt concerned or curious about some aspect of women's health care in your area and wished that someone would look into it further?"
  - "Based on a review of research that has already been done, the following gaps in research were identified: [**insert gaps listed in Wakewich paper here**] How important is it to the women and girls of your community for more research on each of these topics to be done?"
  - The Centres of Excellence do research that involves community members from the start. Do you have any suggestions on how to improve this model?
  - Are there any other issues relevant to policy, research and the health of rural women and girls that you think we should address?
- *Wrapping Up:*
  - "Although all of this information will be given to the Centres of Excellence for Women's Health to be included in the research project, there may be a few themes or issues which have particularly stood out for you as you listened to everyone's perspectives today. What are they? Is there anything else you would like to say?"
  - "I want to thank you for your time and your very helpful contributions. Your willingness to meet with me today makes this focus group possible. The focus groups of women in rural and remote areas across Canada will produce the core of the knowledge that this research project will generate. It could not be done without you. I've been asked by the women who are working on this project who are not here with us today to give you their sincere appreciation for helping in this way. We all hope that by giving our time and expertise to this project that we can make some real changes for women and girls living in rural and remote areas of our country. Thank you very much."

Appendix F
Instructions to Facilitators

This is a community/academic partnered research initiative of the four Centres of Excellence for research in women's health (the Centres) and the Canadian Women's Health Network, funded by the Women's Health Bureau of Health Canada. The co-investigators of this project are Dr. Suzanne MacDonald and Marilou McPhedran of York University in Ontario. The following guidelines were developed by the Research Steering Committee of this project, chaired by Dr. Barbara Neis of Memorial University in Newfoundland and coordinated through the National Network on Environments and Women's Health–NNEWH, the Centre of Excellence based at York University. These Guidelines are to be followed by all of the Centres and their contractors in developing, conducting and reporting on focus groups with women in different regions of Canada, as an integral part of this research initiative. All documents and materials, in original form, as specified in these Guidelines and in the agreements made between NNEWH and other Centres as well as between Centres and those retained by the Centres to facilitate, record and report on the focus groups are to be delivered to Marilou McPhedran at NNEWH, 214 York Lanes, York University, 4700 Keele Street, Toronto, ON M3J 1P3, for further analysis and secure storage. Questions and suggestions should be directed to the Research Steering Committee, through Marilou at marilou@yorku.ca.

Focus Group Outcomes

- Each focus group facilitator should deliver to her respective contracting Centre, which in turn will be delivered by each Centre to NNEWH:
    - The originals of the signed consent forms, as well as the written demographic surveys completed by each focus group participant;
    - A summary of the demographic survey results, without identifying participants, including commentary on who was or was not in attendance and why, with suggestions for improvement, if any;
    - A synthesis report on findings, organized according to the subheadings of the questions beginning on page 3, below;
    - The original audio tapes of the complete discussion of each focus group (identification of the speakers is not expected), as well as the written summary prepared by the focus group recorder, including all questions asked and any answers. Note: copies of the audio tapes may be made and kept by the Centres but not by the facilitators or recorders, unless specific written permission has been granted by agreement with the respective contracting Centre and NNEWH;
    - A list of names and contact coordinates of possible invitees to the National Think Tank in January 2003, drawn from those participating in the focus groups, who have indicated an interest in attending and, in the opinion of the facilitator, would contribute their perspectives actively and add to the diversity of representation at the Think Tank (see consent forms);
    - A list of names and contact coordinates of those who indicated that they would like to receive the final report of this project (see consent forms).

Focus Group Facilitator's Responsibilities

1. The facilitator is responsible for thorough preparation including: a) ordering appropriate refreshments, b) ensuring that the audio-taping equipments and tapes are ready and in working order, c) ensuring that a recorder is in place to ensure full recording of the entire discussion, and, d) arranging for compensation for reasonable expenses. In the focus groups, the facilitator is responsible for explaining the context, expectations and objectives of the meeting, as well as the intended audiences and follow-up plans for any information generated. Wherever possible, we would like facilitators to provide the

consent form in advance to participants of the focus group(s) to give time for review. The following examples, in quotations, of what should be said to the focus group participants are given to assist facilitators and to ensure that focus group participants in different regions receive similar information:

a. *Context:* "This meeting is one of several focus groups around the country. This is the second part of a national project hosted by the Centres of Excellence for Women's Health. The project has an advisory committee, which includes women such as you. We hope to develop a policy framework and research agenda on rural and remote women's health, which can be used by the federal, provincial and regional governments. The first phase was a literature review and roundtable discussion, late in 2001. Later phases will include a national conference in January 2003, followed by a final report to health policy makers and researchers. You are welcome to receive a copy of the final report. Please just leave your name and address on our mailing list."

b. *Objectives of this session:* "Today we'd like to hear your thoughts about health, health care and its availability for you and your community, and other factors which affect your health. We won't be making any decisions in this focus group and we don't expect that we will all agree with each other about many of the points we discuss. But your comments will help us all to reach a better understanding of what health issues are important for women who live in rural Canada. We are interested in what you have to say about the availability and quality of health care services of women you know. We know that women are usually responsible for the health of all their family, but our questions today are not about your personal health or how you help care for family and friends. This afternoon's focus group is a chance to hear your expertise and experience, which will be included in the findings of this research project. We are interested in your opinions of women's health issues in your community."

c. *Follow-up:* "The audio tapes from today's meeting, a written transcript of the audiotapes, a summary of today's discussion and a summary of the written survey that you filled out will be delivered to the Research Steering Committee, and then combined with results from across the country. We will include your thoughts in the research report, which will be part of the national conference on rural and remote women's health in 2003. Finally, a discussion paper with recommendations for a new research agenda and policy framework for rural and remote women's health will be prepared after the Think Tank and submitted to Health Canada. As the focus group facilitator, I am responsible for preparing the summary report on this focus group without identifying any of the individual speakers and I will send you a copy to review before the summary is submitted to the Research Steering Committee. Please let me know if you would also like a copy of the final report and if you want your name listed in the report in our thanks to focus group participants. I need to have this in writing from you, as part of the consent form that you have already signed."

2. The facilitator is responsible for obtaining signed informed consent to participate from each person in attendance, as per the attached consent form IN ADVANCE OF THE FOCUS GROUP. Facilitators should be aware of the parameters of the study (e.g. women will not be asked or encouraged to discuss personal health matters).

3. The facilitator is responsible for ensuring that each participant completes and returns the attached demographic survey at the start of the session.

4. The facilitator should pay attention to who is and who is not in attendance. (For example, how did people come to be there? How might the process of recruitment have excluded some women or points of view? What is likely to be present/absent in the discussion because of who is there?) This will then be reviewed with the Director of the Centre and

included in the focus group summary. Focus group participants should be invited to comment on this concern.

5. The facilitator should then guide the group through a discussion of the topics described below. Facilitators should remember that the discussion should not be limited to health care and service delivery, but should reflect a broad understanding of the social determinants of health, for example, education, economics, laws and policies, social services. It should also adopt both an appreciative and critical orientation, soliciting reflection on both what is and what is not working well for women and eliciting suggestions for achievable, positive changes. Facilitators must ensure that the questions listed are addressed, but other issues that emerge as relevant to participants should also be pursued and noted during the discussion.
6. The facilitator is responsible for ensuring that the session is both tape-recorded and accurately recorded on paper. Doing and/or checking the recording during the session should be the responsibility of a recorder rather than the facilitator.
7. The facilitator is responsible for ensuring a smooth flow to the session, including setting a positive tone, staying on topic, keeping time, taking appropriate breaks, encouraging full participation, and taking the time at the end of the group to thank the participants sincerely for their invaluable contribution of time and expertise, on behalf of all the women who are cooperating on this research project.
8. In some cases, face-to-face small group sessions may not be possible. In order to include women living remotely, the process of data collection may need to be modified through the use of telephone and/or video conferencing.
9. The facilitator is responsible for generating a focus group summary in two parts: one of the demographic data and the other of the discussion themes outlined above.
10. The facilitator should create and hold a master list of focus group participants drawn from the completed consent forms and should assume responsibility for sending copies of the summaries to those participants in a timely manner.
11. In consultation with the Centre, the facilitator should review answers on the consent form and, using her own good judgment, generate a list of potential invitees to the National Think Tank.
12. The facilitator should be prepared to provide the participants with follow-up support or appropriate referrals to community supports (if necessary). It is important to have at least one other person with the facilitator who is present and available to record the group discussion as well as to provide support to participants who could experience some difficulties/challenges that may arise during or as a result of the discussions.

Appendix G

Project Consent Form

SCHEDULE B – Consent Form

[NOTE to the Facilitator: Please try to distribute this form to participants in advance of the focus group and to follow up with a phone call in case there are questions or concerns.]

Dear Ms. _____.

Your name was given to me by _____ who suggested you might be willing to participate in a focus group we are conducting. The focus group concerns health issues for women living in rural and remote areas of Canada. These focus groups have been organized to allow us to hear your voice on the nature of the health services that you have accessed and your assessment of the quality of health care actually delivered over the past decade or so. This is a joint research project with Centres of Excellence for research in women's health in different regions of Canada that has been funded by the Women's Health Bureau of Health Canada. The research in this project is being administered by the National Network on Environments and Women's Health (NNEWH), based at York University in Toronto. Dr. Suzanne MacDonald and Marilou McPhedran are responsible for this study at York University.

The focus groups will be held on _____ from _____ to _____. We are asking for approximately a half-day of your time. You will be provided $ __ to help pay for any costs associated with taking part in this study (e.g. travel and child care costs). This money will be given to you at the start of the focus group session, and will be yours whether or not you refuse to answer any questions or whether or not you complete the session.

The format of the focus group will be a short written survey with questions for you to answer and some additional questions for the group discussion that will help us understand your perspective on services in rural and remote areas, including social programs and social services related to women's health. We will be asking you to suggest changes to policies and practices that would improve your access to services and improve the services available to you, other women and girls. We will not ask you to discuss your personal health matters. You may refuse to answer any specific questions on the survey or in the group. You should also feel free to offer opinions and information on issues or subjects not raised by the facilitator that you think are relevant to this research. You are free to withdraw comments at any time.

After the focus groups are completed and the tapes are transcribed, a draft report containing summaries and unidentified quotes from the focus groups will be prepared. You will be given the opportunity to review the draft report from your group. Results from these focus groups will be compiled and summarized for the project's research committee, which includes community leaders, researchers and policy makers. Findings will also be summarized in a final report to Health Canada from this project and possibly in publications generated from the research. The contents of the final report will be communicated to local communities, health care professionals, and policy makers through a national "Think Tank" to be held in early 2003.

Please feel free to contact York University Human Participants Review Sub-committee with any questions or concerns - research@yorku.ca or telephone: 1 416 736 5055. Requests for copies of the focus group summary should be directed to Marilou McPhedran, Executive Coordinator, National Network on Environments and Women's Health, York University, 214 York Lanes, 4700 Keele Street, Toronto, Ontario, M3J 1P3. Email: marilou@yorku.ca or telephone: 1 416 736 5941; fax: 1 416 736 5986.

I hereby agree to be interviewed in a focus group on women's health in rural and remote areas of Canada, subject to the conditions listed above. I agree/do not agree to be identified by my name in the acknowledgments in the final report.
I am/am not interested in a possible invitation to the national Think Tank in early 2003.

Your Name [please print]: _____

Signature: _____ Date: _____ /02

Address:_____

_____