

Women's Perceptions of the Determinants of Health and Well-Being

Developmental Project

Final Report

Prepared by

Erica van Roosmalen and Charlotte Loppie

Contract Members: Erica van Roosmalen, Karina Davidson, Miriam Stewart,
Susan Kirkland and Dolly Williams

Acknowledgements

We extend our heart-felt thanks to the fifty women from the Atlantic region who participated in the focus group discussions and individual interviews. We appreciate and acknowledge the valued expertise and experience the women brought to the Voices Project. This project could not have been achieved without your thoughtful, open participation and your willingness to share your experiences with us.

We further acknowledge the time, experience, energy, and patience of the project facilitators. You truly made the research process possible. Thank you to Lynne Anthony, Corinne Chappell, Carol Charlebois, Charline Chase, Tracy Chenell, Leslie Hauck, Shelley Kenny, Mary Moore, Clare Parks, Marie Westhaver, and Dolly Williams.

Olive Bryanton, Maggie Cummings, Pratima Devichand, Melanie Farrimond, Angela Gilli, Soledad Gonzalez, Maria Gurevich, Morag Humble, Karen McIntyre, Clare Parks, Carrie Patterson, Lesley Poirier, Liz Townsend, Blenda Vardy-Dell, Shirley Wheaton, Leighann Wichman

Many other women contributed to the success of the research process - from the initial project development, through facilitator training, data transcription, translation and coding, to administrative support. Thanks to the following women for their input and support throughout the research process.

This project was made possible through financial support provided by

The Maritime Centre of Excellence for Women's Health.

Executive Summary

Many community groups and academic researchers have criticized health policy formulation that relies on health experts or traditional key informants alone for insight into women's health needs and concerns. Scant research has explored women's lived realities and how their perceptions of health play out in their everyday lives. Nor has research examined women's participation in social action or policy development in health. In particular, the views and experiences of vulnerable groups of women have been ignored in past health policy research. Given that most existing research has failed to encompass women's experiences and perceptions, we know little about the actual determinants of women's health.

In an effort to not reproduce the biases of past health research, we began by conducting this developmental project on the determinants of women's health. The rationale for this project was to assess the perceived relevance, interest in, and feasibility of conducting a larger more in-depth and intensive study on women's perceptions of the determinants of their health and well-being. As part of the developmental project, we consulted with diverse groups of women to establish: (1) appropriate methodologies for collecting data, (2) strategies for removing barriers to participation of those women who have traditionally been under-represented, and (3) appropriate and relevant research questions.

Through this participatory, qualitative inquiry, 11 community facilitators conducted 11 focus group discussions and 7 individual face-to-face interviews with 50 women. The participating women came from diverse communities within Atlantic Canada (Aboriginal, Black, lesbian and bisexual, homeless, adolescent, senior, military wives, Acadian, Francophone, rural, low income, and women living with physical or mental health challenges).

This initial core project, of the Maritime Centre of Excellence for Women's Health (MCEWH) was conducted with the intent of shaping the scope, direction and approaches of future projects based on the actual lived experiences, perceptions and recommendations of participating women.

This first project was a key opportunity for engaging women in the community, and bringing the MCEWH to the grassroots, through a concrete project which sought their input and perspectives.

It was an opportunity to make connections and to show women we want to take direction from them.

The underlying purpose of this project was to develop appropriate strategies for learning about women's experiences of health, their perceptions of health determinants and the meaning of health in their everyday lives.

Objectives

- (i) to invite the opinions/perceptions of women whose voices have not typically been heard in health research;
- (ii) to describe women's experiences and perceptions of what determines or influences their health, health behaviour and health services use;
- (iii) to understand women's descriptions of health in the context of their daily lives;
- (iv) to further our understanding of diversity within women's health;
- (v) to identify key health related priorities and concerns for women in diverse circumstances;
- (vi) to identify appropriate methodologies and strategies for listening and hearing the voices of women not typically heard.

The *Voices Research Project* begins to fill in some of the gaps in our understanding of the social determinants of women's health and the appropriate strategies for gathering information from women who have traditionally been ignored in the research process. The results are organized in a way that we hope reflect the various circumstances of women's lives.

The results of this study suggest that aside from the obvious biological indicators and lifestyle behaviors that influence the health of individual women, there are myriad social circumstances that leave some women more vulnerable to illness and disease than others. The key determinants of health described by the women who participated in this study include income, education, employment and working conditions, social support, coping, personal health practices, gender, culture, social and physical environments, in addition to, independence, personal control and political environment. At first glance, our results suggest that the participating women's understanding of the social determinants of health closely resembles definitions found in the literature. However, these women's experiences portray a more complex web of the various determinants and the variability with which they play out in the everyday lives of these women.

In fact, the theme of inequality and oppression permeated much of the women's discussion of the determinants of their health. For many women, racial discrimination, ageism, anglocentrism and homophobia represented major determinants of their overall health and well-being. For others, poverty led to a lack of social status as well as inadequate housing and education, or created barriers to accessing health care services and support networks.

A general lack of awareness among health care professionals reveals a need for careful review of current policies, practices and procedures. Health care providers need to be educated about the relationship among the social determinants of health. We need to encourage practitioners to partner with community organizations to increase awareness of the social and cultural conditions of women's lives which impact their health. And we further need to improve cultural representation among health care providers to enhance understanding and empathy and to avoid cultural bias and assumptions.

The results of this study further lead us to conclude that women's health researchers must also be attentive to the potential sensitivity and cynicism of women from marginalized groups, toward white, middle class researchers. Traditionally, women from marginalized groups have been passive subjects in research, rather than active partners. This is especially true for Black women, Aboriginal women, women living under conditions of poverty and women with disabilities, who may feel that they have been "over-researcher" in the past few years. In many cases, these women do not perceive any real benefit from their participation in studies that are presumably designed to improve their health and quality of life.

To ensure that women benefit from the research process, health policy researchers need to work on building community partnerships with diverse groups of women. They need to ensure full and active involvement of all participating women, beginning in the initial stages of research design and remain conscientious of diverse experiences throughout the research process.

It is the conclusion of the *Voices Project* that participatory health research by women, for women, represents an important medium for informing the development of health care policy. It is only in listening to and hearing the voices of women that we can truly begin to understand the ways in which social determinants impact on their health and well-being. We believe that the voices of the women who participated in this project can uniquely contribute to the direction of Canada's health policies.

Table of Contents

Table of Contents	
Executive Summary.....	iii
Objectives	v
Summary of the Research Project	1
1.1 Research Goals.....	1
1.2 Research Objectives.....	1
1.3 Current Knowledge about Determinants of Women’s Health	2
1.4 Methodology	2
1.5 Human Subjects and Ethical Issues.....	5
1.6 Development of Partnerships.....	5
1.7 Data Analysis and Final Results.....	6
Appropriate Strategies for Learning about Women’s Experiences of Health and Perceptions of the Determinants of their Health.....	7
Insights into Diverse Women’s Health Experiences and Perceptions of the Determinants of Health .	9
2.0 Impact on Policy-making.....	16
Lack of Awareness/Sensitivity Among Health Care Professionals.....	16
Lack of Voice in the Policy Process	18
Value of a Participatory Approach to Research	19
Women as a heterogeneous Group.....	20
3.0 Dissemination Plan and Knowledge Sharing.....	22
4.0 Schedule of Activities Carried Out	24
TIMELINE.....	24

5.0 Implications for Maritime Centre of Excellence for Women’s Health Mandates and Research Programs 25

6.0 Financial Report 27

7.0 References 28

Summary of the Research Project

1.1 Research Goals

The overall goals of this developmental project were, first, to develop appropriate strategies for learning about women's experiences of health, their perceptions of health determinants and the meaning of health in their everyday lives and, second, to develop insights into women's experiences, needs and concerns around health and well-being and their perceptions of the determinants of their health. This initial core project provided an opportunity for engaging women in the community, and bringing the MCEWH to the grassroots, through a concrete project which sought their input and perspectives.

One of the intended benefits of this project was to facilitate collaboration between community participants and academic and government persons. The aim was to use this information to develop appropriate strategies/methodologies for conducting a more relevant and informed study of women's perceptions of the determinants of their health and to examine the implications for programs and policies.

1.2 Research Objectives

- (i) to invite the opinions/perceptions of women whose voices have not typically been heard in health research;
- (ii) to describe women's experiences and perceptions of what determines or influences their health, health behaviour and health services use;
- (iii) to understand women's descriptions of health in the context of their daily lives;
- (iv) to further our understanding of diversity within women's health;
- (v) to identify key health related priorities and concerns for women in diverse circumstances;
- (vi) to identify appropriate methodologies and strategies for listening and hearing the voices of women not typically heard.

1.3 Current Knowledge about Determinants of Women's Health

In recent years there has been a developing interest in women's health and well-being and in the social basis of women's health (Walters, et al.,1995). Yet significant gaps in our understanding of the social determinants of women's health remain. Attention to gender as a social construct embedded in a political arena, recognizes that there are powerful social and political factors that influence the quality of women's health. The history of exclusion of women from health research resulted in a view of health predicated on a male model (Clancy and Massion, 1992; Cotton, 1990a; Cotton, 1990b; Dresser, 1992). This exclusion has significant implications for the management of all women's health (Council on Ethical and Judicial Affairs, American Medical Association, 1991). The model also presumes that health and well-being hold the same meaning for women and men, and that interventions will have the same positive health outcome for women.

The restricted and narrow focus of women's health research does not take into account the diversity of women's lived experiences. Although we recognize the importance of understanding the experiences women share, it is equally important to acknowledge the differences among women. We know that women view their health and well-being in an inter-relational framework that encompasses social, cultural, psychological, spiritual, and biological dimensions. For this reason, it is essential that we begin to address women's health and well-being from the standpoint of women themselves. Our interest focuses on the perceptions and definitions of health and well-being that are grounded in women's daily experiences. Recognition of the complex and multi-faced nature of women's life experiences, and the powerful underlying determinants of health which traditionally fall outside of the scope of health research are central to the improvement of women's health

1.4 Methodology

Through this qualitative inquiry, we sought to understand the perceptions and experiences of the determinants of health among diverse groups of women throughout Atlantic Canada. Additionally, our intent was to explore various recruitment processes that might be helpful in identifying and recruiting 'marginalized' women from across the Atlantic region to take part in research at both the participant and facilitator levels. Moreover, as we were particularly interested in hearing the voices of women who have been ignored and/or marginalized in past health research, this study specifically pursued strategies for locating and involving those groups of women.

By employing a stratified/purposive sampling technique, we were able to identify diverse groups within the Atlantic region on the basis of geographical representation and life circumstance. The criteria, which emphasised vulnerable groups, included (1) ethnic/cultural identity (e.g., Aboriginal, Indigenous Black, and young Lesbian and Bisexual women); (2) isolated regions (e.g., coastal communities, rural areas); (3) women living in poverty (e.g. Social Assistance, homeless, unemployed, single parent); (4) adolescents; (5) seniors; (6) women with physical or mental health challenges; (7) Military wives; (8) language (e.g. Acadian and Francophone women). Our intent was to ensure that women from a wide range of backgrounds, from each of the four Atlantic Provinces were included as participant facilitators. Eleven facilitators were solicited from organizations associated with the Maritime Centre of Excellence for Women's Health as well as through personal, professional and community networks (see Appendix A - Facilitator recruitment letter).

Prior to conducting the focus groups and individual interviews, facilitator training sessions were held via tele-conference calls. The primary purpose of the training sessions was to share with facilitators specific skills training related to participant recruitment, group facilitation, individual interviewing, listening, recording, and lobbying. The training sessions also included direction and discussion around: the goals and objectives of the Women's Voices project, the role and responsibilities of facilitators, the rights and responsibilities of participants, and the potential utilization and application of the information gathered.

The facilitators used network sampling to recruit a total of 50 women from their respective communities who might be interested in participating in the study. In an effort to be as thorough and inclusive as possible, the facilitators conducted a series of 11 focus group discussions (between 4 and 7 women in each group) and 7 individual face-to-face interviews. These group discussions and interviews lasted between 1½ - 2 hours. According to Denzin (1978), triangulation of research methods reinforces theory that emerges from the data. Within this study, the use of both focus groups and individual interviews represents a more comprehensive approach to discovering the meaning women assign to the determinants of their health and relating those experiences to the larger social context. Moreover, both of these qualitative methods allow participants to express their perspectives using their own words (Patton, 1990).

Given that we planned to compare the views of women from different backgrounds and life circumstances, each focus group was relatively homogeneous with respect to the general characteristics of the participants (i.e. Aboriginal women, Military Wives, Acadian women), but diverse in terms of each woman's specific life experiences. It was anticipated that the participant women would feel more comfortable sharing their personal views and experiences with women of similar social, ethnic, or cultural circumstances. In fact, the literature documents numerous studies that use social comparison theory to explain why self help group, support group and focus group approaches tend to yield more useful information if participants hold important background characteristics in common (Stewart, et al., 1997b; Gottlieb, 1996; Morgan, 1992; Calder, 1977; Smith, 1972).

However, some women did not feel comfortable sharing their voice in a group format and others simply found it more convenient to participate in a more personal rather than group setting. Individual interviews provided a safe, private context within which participants could explore their perceptions of the determinants of their health. The use of this method also permitted us to gain a more in-depth and holistic understanding of women's respective perceptions and realities as well as how they attach meaning to the determinants of their health (Patton, 1990).

In consultation with the facilitators, each participant was free to choose whether they wanted to participate in an individual interview or focus group discussion. All individual interviews and focus group discussion were conducted at a location and in the language of the participants' choosing. All supporting documents were translated into French for use with Francophone and Acadian women.

Although both the group and individual interviews were conversational and somewhat free-flowing, a semi-structured interview guide provided direction in terms of achieving the fundamental purpose of data-gathering for this study (See Appendix B). The interview guide included eleven general questions focussing on women's perceptions and experiences of the determinants of their health as well as women's recommendations for identifying and conducting research with women from diverse circumstances and for improving women's health. This guide was open-ended and flexible enough to promote discussion of issues surrounding women's health in a way that was meaningful to the diverse groups of women, yet structured enough to allow for inter-group comparisons. By keeping the interview format flexible, facilitators were able to stimulate discussion of issues introduced by participants, which were not included in the interview guide.

1.5 Human Subjects and Ethical Issues

In this study, the women were only asked to provide oral statements about their own experiences and perceptions of women's health issues. Voluntary consent, confidentiality, protection of anonymity, and fair representation of the information given are the central ethical issues. Prior to beginning the study, we obtained ethical consent from the Faculty of Graduate Studies Ethics Committee at Dalhousie University (See Appendix C).

The women were fully informed as to the nature of the study. They were assured confidentiality and that they could withdraw from the project at any time (see Appendix D - letter of introduction, Consent Form, etc.). Refreshments and a nominal honorarium of \$25.00 were provided to participating women. Child care and transportation expenses were also paid when necessary.

1.6 Development of Partnerships

The Research Team represented a multi-disciplinary, inter-sectorial group of women from community organizations and academic institutions. The initial Research Team was selected based on the breadth of their experience and interest in the areas of women's health and their commitment to pursuing the mandates of the MCEWH. Women from diverse communities played a key role in assuring representation and sensitivity throughout the research process.

A close working relationship was also maintained with the *Priorities* research team to ensure that the project's findings reach a broader spectrum of Nova Scotia community women and policy makers. Preliminary comparative analysis between the survey on women's perceptions of their health and this qualitative study have been initiated. The *Women's Voices* project has also enabled us to establish links with other researchers working in the area of women's health such as the Nova Scotia Gynaecological Cancer Screening Programme and the Women's Wellness Centre (IWK-Grace).

The project team has also communicated and consulted with similar CEWHP project teams. Communication with other Centres has included sharing the proposal, preliminary/pilot findings, and literature reviews. In particular, the project team has asked other Centres to share these materials with their project teams. Throughout the pilot study, consideration has been given to developing a proposal for additional funding to conduct a more comprehensive, comparative study within Atlantic Canada.

It is our belief that we can inform the development of a comprehensive larger study on women's perceptions of the determinants of their health and well-being in five ways: (i) by improving the understanding of diverse gender-specific perspectives and experiences of health determinants; (ii)

by including diverse groups of women's understanding of the experiences, perceptions and knowledge of determinants of health, health behaviour and health services use; (iii) by identifying appropriate research methodologies and strategies for locating and including marginalized groups of women; and (iv) by identifying health priorities as understood by participating women; and (v) by building into the research design a collaborative community-academic research partnership.

1.7 Data Analysis and Final Results

This qualitative inquiry was informed by a Hermeneutic approach to understanding the social, economic, political and environmental determinants of women's health. The initial stage of this research was exploratory in nature. After each of the individual interviews and focus group discussions, the tapes were transcribed (and translated). Each transcript was read and coded by two members of the research team and one independent coder. Five facilitators also participated in coding their own interview and focus group discussion. The transcripts were coded based on the determinants of health model (Health Canada, 1994; Stewart, et al., 1997), although, the coders were free to add additional determinants that were not predefined by the model.

In recent years, there has been a developing interest in women's health and well-being as well as in the social basis of women's health. Yet, significant gaps in our understanding of the social determinants of women's health remain. We hope this research begins to fill in some of these gaps. We have organized the results in a way that, we hope, reflects the various circumstances of women's lives. Although we have identified diverse conditions under which women live, it is not our intent to isolate women into particular categories. However, in order to identify specific health issues, we must first discover how divergent paths lead women from diverse backgrounds to the same destination in terms of their health. Recognition of the complex and multi-faced nature of women's life experiences as well as the powerful underlying determinants of health, which traditionally fall outside the scope of health research, is central to the improvement of women's health.

Despite the diversity of participating women's life circumstances and their experiences of the determinants of health, an overriding theme emerged from the research findings that relates to issues of inequity and oppression. In fact, this theme permeated much of women's discussions of the determinants of their health. For the women who participated in this study, gender as a common source of oppression was intensified by its association with a complex web of immutable and insurmountable conditions that formed barriers to women achieving optimal health and well-being. These varied and overlapping sources of oppression included race, ethnicity, culture,

age, language, rural/urban status, socio-economic status, sexual orientation, housing status, as well as physical and mental challenges.

Traditional determinants of health frameworks are based on the experiences of women who belong to dominant social groups. Conversely, the women who participated in this study belong to groups about whose health needs and concerns we know relatively little. It is not surprising therefore, to discover that the very social conditions that marginalized these women in past research also represent the most insidious and devastating detriments to their health.

Appropriate Strategies for Learning about Women's Experiences of Health and Perceptions of the Determinants of their Health

When researchers fail to recognize all sources of female oppression, disadvantaged women become further marginalized in the research process. One of the central lessons learned from this research is first and foremost, women's health researchers must be attentive to the potential sensitivity and cynicism of women from marginalized groups, toward white, middle class researchers. Traditionally, women from marginalized groups have been passive subjects in research, rather than active partners. This is especially true for Black women, Aboriginal women, women living under conditions of poverty and women with disabilities, who may feel that they have been "over-researcher" in the past few years. In many cases, these women do not perceive any real benefit from their participation in studies that are presumably designed to improve their health and quality of life.

We need to be listened to. We need to get something done... It goes in one ear and out the other. Why keep asking us the same questions over and over and over when they are not going to do a damn thing about it. (Aboriginal Women)

In an effort to ensure full and active participation in this project, Voices team partners included women from diverse backgrounds who represent various perspectives (ie., race/ethnicity, culture, religion, language, socio-economic status, housing status, sexual orientation, age and ability). In keeping with the principles of participatory research, team partners assumed a side-by-side, rather than a top-down approach to the research design and process. This is particularly important in collaborative research between academics or health professionals and community/grassroots organizations.

Trust is the biggest think. If they don't trust them, and if they aren't Aboriginal, they won't show. Of if they do show they won't say anything..... Yes, everybody feels comfortable because everybody know everybody. And why you take somebody in the authority position or somebody who has that label of authority, they are not going to open up to them no matter what they say.

A participatory approach was most appropriate for this study because it encouraged an equitable research partnership between women from academic and community backgrounds. This alliance was formally instituted through a partnership agreement that was developed and signed by participating facilitators and research team members (see Appendix E). However, perhaps the most meaningful reflection of this partnership took shape in less formal ways such as

- providing facilitators and participants with honoraria that reflected the value of their time and their contribution to the project
- remaining conscientious of diverse experiences in the review of interview questions and inviting feedback from all facilitators
- employing methods that “work for women”, such as group and individual interviews in which women had an opportunity to frame their experiences within the context of their everyday lives
- providing an opportunity (ie: methods journal - Appendix F) for facilitators to document and comment on the research process as it relates to recruiting participants, arranging meeting times/places, and the interview process
- ensuring extensive participation of facilitators during the analysis phase of the project

Through mutual respect and true membership, partners of the Voices team were successful in overcoming many of the challenges inherent in participatory research. Team partners embraced the concepts of partnership and affiliation throughout the research process in the following ways:

- by embracing the rich diversity of women’s experiences, insights and knowledge by inviting the participation of women from different backgrounds
- by forming community partnerships with diverse groups of women, particularly those whose voices have been ignored in previous research agendas
- by identifying and treating every women involved in the project as a research team partner

- articulated and demonstrated an understanding of the crucial role that participants and facilitators play in the research process
- by enabling full and active participation of all research team partners, beginning in the initial stages of research design
- by developing a multi-layered perspective of the research objectives, design and process
- by conducting the study in a manner that did not constrain, intimidate or neglect research partners
- by engaging in ongoing and personal communication with research partners
- by ensuring that meeting places that were accessible to all partners and that meeting times were respectful of women's busy schedules and multiple responsibilities
- by developing trust and rapport by focusing on the research needs of participants rather than the needs of the project
- by addressing participants concerns directly through the sharing of information and the process of compromise
- by listening and responding to women's voices; particularly those who have been silenced or ignored in the past

Insights into Diverse Women's Health Experiences and Perceptions of the Determinants of Health

The results of this study suggest that aside from the obvious biological indicators and lifestyle behaviors that influence the health of individual women, there are myriad social circumstances that leave some women more vulnerable to illness and disease than others. The key determinants of health described by the women who participated in this study include income, education, employment and working conditions, social support, coping, personal health practices, gender, culture, social and physical environments, in addition to, independence, personal control and political environment. At first glance, our results suggest that the participating women's understanding of the social determinants of health closely resembles definitions found in the literature. However, traditional definitions typically ignore how the social determinants are perceived and experienced by diverse groups of women. These women's experiences suggest that

the impact of health determinants is also a function of their unique social circumstances. In fact, one of the most unique features of this study's findings is the complexity and interrelatedness of the various determinants and the variability with which they play out in the everyday lives of these women.

For many women, racial discrimination, ageism, anglocentrism and homophobia represent major determinants of their overall health and well-being. For others, poverty leads to a lack of social status as well as inadequate housing and education, or creates barriers to accessing health care services and support networks.

For example, Black women reveal that their marginal utilization of preventive health programs and services is largely based on their perception of racial and social bias within the health care industry. In particular, these women suggest that the discriminatory practices of many health care providers represent a powerful determinant of Black women's health.

Racism has played a lot of stress factors on the health of black women... Well, first of all, you're a black woman and when you go to a doctor before, they didn't have a lot of black doctors to go to. And women shy away from doctors. Black women feel that they can heal themselves. ... Because of the stereotypes and how they look at us and see us, women don't go because they look at us as, "Here comes another one. These poor people coming in here that are going to bleed the system." So women stay home and heal themselves. By the time they would get there, it's too late.

I think the most important issue right now is the perception. Because the health care practitioners that are mainly from the mainstream, white society perceive the black women, black culture, black women as being passive. The moment they walk in, it's like they already have their perception of what they are so they are treated differently. And so health care providers do not provide the health that black women need for them. I don't have a lot of confidence in health care facilities even though I was a health care worker for a number of years. Because I've seen it, firsthand, the difference in treatment between cultures.

Aboriginal women also talk about how inaccessible or culturally inappropriate programs and services, delivered by non-Aboriginal health care providers, do little to promote the health of Aboriginal people. This lack of social support is compounded by issues of literacy and unemployment to create a cycle of poverty, experienced disproportionately by Aboriginal people.

In my situation if I was sitting at home, if I wasn't out here earning a living and I was sitting at home, I would have all the care in the world with Social Services home care and support. But when you are out and you are making enough money that you don't get Social Services, it's hard to tap into home care and support. Because they just don't have the lists available. They don't have the resources either. Why they don't advertise is beyond me, but they don't.

There are a lot of people who won't allow a non-Aboriginal to come into their home. They would rather ... If there is no Aboriginal women or me to come in then they'll just live without. A lot of our elders are like that. They would rather have an Aboriginal come in. And our elderly women are very strong on that.

I think literacy too could be a factor... Because if someone is unable to read, they are unable to cook because they won't be able to make these recipes... Or a job application... Reading labels... Unable to read what is good for you.... I went with someone who is illiterate, and she always bought brand names because she didn't know any better. And so of course she is spending more money on brand names where no-name brands would be just as good but she didn't know the difference, because they are cheaper. ... A lot of people who are illiterate will just go based on the colour. Like a friend of mine, he is illiterate. And his wife normally did all the shopping but she got sick so he had to go do the shopping. And all he understood was the colours of each product. So he went and he was supposed to get a can of coffee and it was a yellow can and he ended up getting a can of baking powder because both cans were yellow.

The anglocentric culture of Canadian society creates significant barriers with respect to the social determinants of Acadian women's health, such as education, employment, health services, and social supports.

[Acadian woman] would like to volunteer to do work, but she can't because her literature and her program was all in English... she's not English but her work is in English. A lot of my work is in English and I really have to work hard.

You always have to fight that... it's a worry that we've always had as a population to be accepted with our language... that's how we express ourselves.

The anglocentrism and patriarchy of the Armed Forces, as a microcosm of mainstream society, creates a myriad of additional barriers for Francophone women, particularly with respect to accessing health services.

A dentist and everything like that. And I should do it in their language but not my language. And I found a psychologist. It was hard for me to find one, a francophone. Because it's not the same thing if you explain your emotion in French than in English. You know, because we are francophone, the last place that we will have is Quebec. We don't have the choice.

The first think is because I am Francophone. And the army don't take us, the women, francophone, don't give us the opportunity to learn... My husband is bilingual. And he's francophone first, and he should learn ... he must learn English. But I am francophone. His wife is francophone. And the army don't consider it that I am francophone. And it's hard for me to find a job in an anglophone province. And I think the situation is hard for us to lean another language, and to find a job in not my language, and to translate all my thinking in all the language.

The women's discourse suggests that the oppression they experience as the wives of service men, living in the confines of a military culture act as powerful underlying determinants of their health.

I want to keep my husband home. I was really far from my family, and my husband leaves. And this situation really affects my health. If I am far from my family, and my husband is gone, my health is really affected. It is hard because I don't have my mother to help me or my sister. You know, I should pay a babysitter all the time if I want to do something.

And what about independence? I think that is a good point for health too, is independence or strength. I mean I have met a lot of military wives who have no drivers license. So even if the husbands are away, they rely on a neighbour or somebody close by because they cannot drive... you are very dependent on somebody else. I think it is scary.

Perhaps the most serious threat most lesbian and bisexual women face, with respect to their overall health and well-being, is the homophobic culture in which they live. Evidence suggests that stress, and nervousness among lesbian and bisexual women is an outcome of life stresses related to homophobia and discrimination.

I think just dealing with homophobia in general, that causes a lot of stress. And just trying to be yourself and do whatever, and not getting the acceptance that you need, that is detrimental.... Going to your workplace³ and first of all having to decide whether you are going to tell these people that you are lesbian or bisexual. Second of all, deal with them when you do. And everyday, you go in there and if you are not out, you have to play a game where you are somebody that you are not for all those people that you are not out to... I meant it's hared to be two different people.

The determinants of gender and age combine to uniquely influence the health of senior women. For these women, patriarchy overlaid with ageism serves to negatively influence important determinants such as income, social supports and access to health services.

If the father dies, the family put a lot of pressure on the mother to sell the family home. Even though the family might have seen that it was mother that was making all the decisions on the household anyway, all of a sudden if the father dies then they think their mother can't cope in the home. ... Not only that but they feel as if they had the mother in an apartment or a senior residence that then there is less stress on them.... Yes, less responsibility... But also there is a lot of pressure goes on the woman to leave the family home. The family feel they can make a decision for their mother where they don't feel they would make that decision for their father. The father is left to control, even if it was the mother who was in control all the life time. And the pressure, I have seen people move into senior housing because there was so much pressure put on the family, by the family doctor, by the pastor.... It's incredible how women are affected that way rather than men.

The multi-faceted nature/quality of social support clearly resonates in the voiced experiences of diverse groups of women. For some women, access to social support not only enhances their capacity to cope with life stresses and illness but also has been shown to improve their overall mood and increase their life chances.

I think hope is one of the most important things. Connections Club House gives us hope that there is something better, and that we can achieve and we can be productive citizens, maybe not tomorrow or the next day, but somewhere in the future. (Women living with mental health challenges)

I would be a statistic. I would be dead. This non-profit housing saved my life. And how many places don't have this? How many areas? Rural areas don't have this. (Homeless Women)

If you are going through trouble and there is somebody to turn to, it's not really going to solve your problems but talking can help you get through it. (Adolescent women)

Family is important, and they can be your anchor. But if they are not supportive, the boat is going to sink. You come from your family. They are supposed to be your whole support network. They are the only support you start off with. So if they are not supportive of anything about who you are then you've got nothing when you start out. You've got to go by yourself. Basically they are not your family anymore. Like in name and blood and everything, they are still your family. But emotionally, the support is just not there. (Lesbian and Bisexual women)

I think that is one thing that keeps a lot of lesbian, gay and bisexual people together, is that they realize that they have... In order to be healthy, they have to choose their family. And they draw away from their traditional family that they were either born or adopted or got into. And they pick the people that they want to choose to be their anchors because it is so important to have someone – people who support and love you and care for you, whether it's who you started out with or not. (Lesbian and Bisexual women)

However, a lack of awareness in the planning of community supports may negatively impact the health of women. Rather than providing much needed assistance, social services that have not

been appropriately tailored to housing and ability status for example, create additional burdens and stress for women living with health challenges.

Did you ever try to get it through disability-related needs? I tried to get a washer and dryer because Homecare said they don't go to laundry -mats, and my washer broke down. And it was going to cost \$175 to fix it, and Social Assistance wouldn't pay to have it fixed, and they wouldn't buy me a new one. Now if my Homecare workers won't do the laundry at the laundry-mat, and I can't do it, how in the heck are you supposed to have clean clothes? These are disability-related needs, you know. I can't wash clothes by hand.

Especially in the summer, you go to the food bank thinking you're going to get enough food to do you until the next time. There's nothing there. What there is there, ...it's stuff that doesn't last you more than three days. There's no fresh fruit, vegetables, protein, hardly ... If your primary is the food bank, then tomato soup and beans are what you live on. And moulded bread. I know my experience with the food bank is a lot of it is bad. If they give me fruit, it's not edible. They think that homeless people will eat rotten fruit. (Homeless Women)

Rural women also face insurmountable social barriers to accessing services that maintain or improve health. For these women, issues of poverty, geographic and social isolation, lack of social support, and an urban-centric health system, combine to not only undermine their overall health and increase their vulnerability to illness but also contributes to the quality of family care.

I have a van. And I have the license plate in my name, but I don't have money for insurance so I can't drive the van. If I want to go over to my mother's ...Like if something happened here, I have no phone... if something happened to one of the ids, I would have to .. If I just felt like going out for a drive, like if the kids were cranky or whatever, I can't do it. I used to be able to. And it is hard. (Single mom living in a rural area)

Inequality, in any form, diminishes women's perceived control and increases their stress which, among other things, can lead to greater vulnerability to disease. Essentially, inequality and

oppression translate into less access to the resources that facilitate the maintenance and improvement of health.

2.0 Impact on Policy-making

It is only in listening to and hearing the voices of women that we can truly begin to understand the ways in which social determinants impact on their health and well-being. We believe that the voices of the women who participated in this project can uniquely contribute to the direction of Canada's health policies.

Lack of Awareness/Sensitivity Among Health Care Professionals

Throughout the *Voices Project*, the participating women continued to express their concern with the lack of cultural sensitivity and awareness on the part of the medical profession. For many of these women, racial discrimination, ageism, anglocentrism, and homophobia represent barriers to quality health care.

There is not that much help out there as far as home care and support. They tend to talk about it but when it's actually needed it isn't always available. So a lot of stress falls on the older woman to be the caregiver, and her health can suffer drastically as a result of it. And I don't think the medical profession even think about that. (Senior Women)

There is a lot of misinformation. That is one of the problems I have with the doctors here.... I mean I was a very young mother, and the attitude was very condescending... I took her to the doctor and I said, "You know, there is something wrong. This has been 3 weeks of this." And he basically sat me down and patted me on the shoulder, and he told me that I was never going to make it through a year if I didn't stop being such a hysterical mother. (Rural women living in conditions of poverty)

First of all, I really, really, truly believe that the doctors have to be retrained. There's so much poverty, and if the doctors are used to the people with money coming in, that's only because the poor people are suffering and not coming in..... The way he spoke to me was" Well, you know, why don't I just put you on this drug?" I said, "I can't get on this drug. It makes me a zombie. I can't function during the day, I can't do anything" He responded by saying ".... you're better off, even if you're

lethargic during the day. Just go on disability.” ... Basically, what he was telling me was Let’s put you on these nerve pills and take your life away. Instead of trying to find the reason why you’re not being productive, and let’s get you productive, let’s make you into somebody that’s going to be on welfare, on nerve pills, for the rest of her life. And that will be ok, because you’re a woman. Or because you’re somebody who’s come in here without money and power. That’s the attitude that’s out there in the health profession. They see us as different species. (Homeless Women)

I think the most important issue right now is the perception. Because the health care practitioners that are mainly from the mainstream, white society perceive the black woman, black culture, as being passive. The moment they walk in, it’s like they already have their perception of what they are so they are treated differently. And so health care providers do not provide the health that black women need. (Black women)

I am pretty sure, doctors and nurses and those types of health professionals get very little with regard to sexuality. They are taught about risk factors in things when it comes to straight women but I don’t think they are taught much about risk factors for ... different kinds of cancers or sexuality transmitted diseases or anything when it comes to lesbian and bisexual women. I think there is a big area of education that is lacking right there. (Lesbian and Bisexual women)

Understanding, empathy. They can put themselves in your place as opposed to making decisions for you and assuming a lot of things. Assuming that you are not disabled because it may not be visible at times. But especially like in Community Services, those departments, Homecare, those are key. You need people there. In most of those places there are no people with disabilities at all. And especially the medical profession. ... They should have a more holistic approach, and they should be sensitized to a person with disabilities. And maybe even for a week or something, be in that position that a person with a disability would have to face, and understand it. Because they are crucial to whether you go on and be an active and productive part of society, doctors are. (Women living with physical disabilities)

Policy Advice

A general lack of awareness among health care professionals reveals a need for careful review of current policies, practices and procedures. Policy recommendations include:

- encourage further education of health care providers about the relationship among the social determinants of health
- encourage practitioners and educators to partner with community organizations to increase awareness of the social and cultural conditions of women's lives which impact their health
- improve cultural representation among health care providers and other educational leaders to enhance understanding and empathy and to avoid cultural bias and assumptions

Lack of Voice in the Policy Process

It is clear from the women who participated in the *Voices Project* that their health needs and concerns are not being addressed by existing policy. They believe this is a direct result of their not being asked to participate in decisions about the content, appropriateness, and allocation of community resources and services.

*Policies have to come from the bottom up and not from the top down.
(Senior Women)*

I think they should come into the communities and say, "Well, instead of maybe putting in some programs...." Maybe if they came in and had a group even like this, or a couple of them, and said, "Alright, if we're going to spend any money here, what is the one thing or the top three things that you would want us to spend the money on?" Instead of just saying, "Alright, we're going to give this community \$50,000 and they're going to use it to expand the library," or to god knows what. (Rural Women)

Listen to the people. I think that is the most important thing. I mean right now government is saying we consult. Well, bologna. They have their chosen few who are supposed to be representative of society. If we had more grassroots, more community development types of programs that

would be meeting the needs of the people. But the communities can say, “Look, we want this, this and this,” and government will say, “No, no, you have that, that and that, and we’re not going to give you this, this and this.” ... Let the communities decide what it is they need. Since government has our tax dollars then government should divvy it out to the communities. (Senior Women)

We don’t have an idea of what it would be like to talk about our health because no one has actually ever asked really. (Lesbian and Bisexual women)

Policy Advice

In general, health policy formulation relies on health experts or key informants alone for insights into women’s health needs and concerns. Policy recommendations include:

- identify key grassroots community women who play an active role in promoting and advocating for women’s health in their community
- invite these women to participate in the decision making process as it applies to their communities’ health needs and concerns

Value of a Participatory Approach to Research

To date, there is little information generated by participatory research with which policy makers can make informed decisions regarding social change. However, it is not enough to simply invite women to participate in a public forum. For marginalized women in particular, the invitation to participate needs to come from representatives from their own community.

... we need to go further... to get more women involved... It’s not just the government’s responsibility, it’s the community’s. (Acadian Women)

Hold community meetings, community workshops. Place somebody there that they know – outreach workers. If you’re going to a reserve, get an Aboriginal facilitator from that reserve. Somebody that they know rather than having a complete stranger, a non-Aboriginal come onto the reserve and start speeling off to them. They are going to think, “Who the heck are you?” Like do you think you would have got this many women here if it

hadn't been for this centre (Mi'kmaq Friendship Centre) that was putting it on?

Policy Advice

Participatory health research by women, for women, represents an important medium for informing the development of health care policy. Policy recommendations include:

- form community partnerships with diverse groups of women, particularly those who have been ignored in previous research
- ensure full and active involvement of all participating women, beginning in the initial stages of research design
- remain conscientious of diverse experiences in the review of research questions
- employ methods that “work for women”, such as group and individual interviews in which women have an opportunity to frame their experiences within the context of their everyday lives

Women as a heterogeneous Group

Traditional social determinants research has done relatively little to expand measures of social support, culture, social environment, working conditions, personal health practices and coping skills beyond the boundaries of the dominant culture. There is a massive investment in the collection of health data information at every level of government in Canada. This information is being used everyday to make policy decisions. Policy decisions, however, are rarely based on the results of in-depth, qualitative studies but rely instead on broad, quantitative studies which do not necessarily reflect the heterogeneity of women in Canadian society.

If people are out of the norm, then you can be sure that what you get in terms of service is not going to be the same. Good or bad, it's not going to be the same. And we have to find that balance... And so it's like how do you do that? And that should not be to our accountability as the women. That should be to the system's accountability. It's not for us to make the change. It's for the people who are supposedly meeting all of our needs to make the changes. I would hope that a study would say that. That we all

are aware and recognize the reality of people's histories and how they have been treated. (Black Women)

Policy Advice

Recognition of the complex, multifaceted nature of women's life experiences are central to the improvement of women's health. We believe it is vital to make use of the results of qualitative studies to help guide the development of population-based data sets, to ensure that they reflect the cultural diversity of women's lives. Policy recommendations include:

- educate funding agencies about the value of in-depth, qualitative research and the time required to conduct true participatory research projects
- encourage "tiered" research that begins with a participatory approach to gathering qualitative information which can then be used to inform large-scale, quantitative survey research

3.0 Dissemination Plan and Knowledge Sharing

Given the participatory nature of the Women's Voices Project knowledge sharing and dissemination have been critical components of the research process. In addition to the ongoing consultation process, we have also shared our preliminary research results through conference presentations and journal submissions. Refer to the list below.

van Roosmalen, E., Loppie, C., Stewart, M. and Davidson, K. "Sharing Women's Voices: Women Define Social Support as a Key Determinant of Health." Submitted to Canadian Journal of Public Health (1999).

van Roosmalen, E. "Women's Voices: The Perceptions and Determinants of Women's Health and Well-being-- Refereed Abstract," 5th National Health Promotion Research Conference Proceedings, Dalhousie University, July 4-5, 1997, Halifax.

Loppie, C. and van Roosmalen, E. "Determinants of Marginalized Women's Health and Well Being: A Review of the Literature." Maritime Centre of Excellence For Women's Health Resource Document, IWK Grace Health Centre, Halifax, Nova Scotia, 1998.

"Sharing Women's Voices." Women's Worlds 99 - 7th International Interdisciplinary Congress on Women. 20-26 June, 1999, Tromso, Norway (with E. van Roosmalen, C. Loppie and K. Davidson).

"Women's Voices: Taking Account of Cultural Diversity." 12th Canadian Heart Health Network Meeting – Taking Action on the Determinants of Health. Nov 15-18, 1998, Halifax (with C. Loppie and E. van Roosmalen).

"Women's Voices: Women's Perceptions of the Determinants of Health and Well-being." Poster presented at the 5th National Health Promotion Research Conference, Dalhousie University, July 4-5, 1997 Halifax, Nova Scotia (with E. van Roosmalen, M. Stewart and C. Charlebois).

There is a general lack of awareness among privileged researchers regarding the power dynamics inherent in research and between communities of women. Consequently, little effort has been made to write in plain language or to disseminate the findings of most studies beyond peer reviewed, academic literature.

Beyond academic circles, we submitted a Social Support News Brief to the Canadian Women's Health Network (forthcoming) 1999.

The *Voices* and *Priorities* Research Teams are also working together to develop and distribute a series of brochures (in consultation with the facilitators) on the determinants of health for diverse groups of women. These brochures will be distributed to participating women, community groups, resource centres, health professionals and to women who play an active role in promoting and advocating for women's health in their community.

4.0 Schedule of Activities Carried Out

TIMELINE

Women's Voices Proposal

June 1997- October 1997

- Initial proposal development by academic and community members through a series of workshops and teleconferences
- External Review Process
- Revision of proposal according to feedback from External Review Committee

Women's Voices Resource Document

June 1997 - July 1998

- Literature Review and Document Search
- Completed Resource Document
- Resource Document circulated to all Centres' of Excellence for Women's Health and to various individual and community members

Interview and Focus Group Guide Construction

October 1997 - May 1998

- Developed initial questions to be used in focus groups/interviews through a series of workshops
- Developed focus group/individual interview guide
- Developed supporting documents (letters of introduction, consent forms, honoraria receipts, methods journals etc.)
- Pretested guide

Facilitator and Participant Recruitment

April 1998 - June 1998

- Facilitators were recruited through MCEWH networks and personal, professional and community connections
- A series of teleconferences and face-to-face workshops were held to train community facilitators in focus group and interview processes
- Refined interview guide and supporting documents based on facilitator feedback

- Facilitators recruited participating women for focus groups and individual interviews based on community networking
- In consultation with facilitators a partnership agreement was developed and signed

Data Gathering and Management

June 1998 - August 1999

- Focus groups and individual interviews were held within each of the Atlantic provinces
- Transcribing of tapes
- Teleconference with facilitators to develop determinants framework for coding
- Coding of textual data

Data Analysis

September 1998 -

- Preliminary data analysis using both content and textual analysis
- Ongoing consultation with participant facilitators
- Data analysis is ongoing

Final Report and Reporting of Preliminary Findings

March 1999 - August 1999

- Preliminary findings were reported at various national and international conferences
- Preliminary evaluation and discussion of research process with facilitators
- Submission of Final Report to MCEWH

5.0 Implications for Maritime Centre of Excellence for Women's Health Mandates and Research Programs

As a core project of the MCEWH, *Women's Voices* epitomizes the Centre's first program of research - *women's perceptions and the determinants of their health* and the second program of research – *determinants of health of marginalized women living in disadvantaged circumstances*.

The members of the *Women's Voices* project have sought to actively contribute to the MCEWH mandate that emphasizes the accumulation and consolidation of knowledge, participatory research and policy initiatives. This project is also consistent with the Centre's mandate to influence and direct policy about women's health. This core project has helped to shape the collaborative process that is seen as the cornerstone of all knowledge generation by collaborating with (i) women from isolated and diverse communities (ii) community organizations that provide services to women

from disadvantaged groups and (iii) academic representatives who are active in research aimed at improving women's health. The interdisciplinary and inter-sectorial nature of this project will likely influence the scope, direction, and setting of priorities for future projects conducted through the Centre through the facilitation of partnering with women from diverse backgrounds. It is our hope that the knowledge generated from this project as well as the "lessons learned" from this participatory approach will also be used by our Centre to inform future knowledge generation projects and provide information to those professionals targeting women's primary health concerns.

The unique contribution of the knowledge generated from the *Women's Voices* project began with the participatory process used to develop a connection with women from marginalized or isolated communities. This process helps to ensure that a diversity of knowledge and experience is brought to bear on policy decisions regarding the determinants of women's health. In particular, issues that are specific to women from vulnerable ethno-cultural groups. These new insights on the determinants of health reflect the unique social circumstances that influence the everyday lived experiences of diverse groups of women. The knowledge generated from this research builds on and reflects individual women's experiences, rather than attempting to "fit" their experiences into a predefined determinants framework.

6.0 Financial Report

Project Title: Women's Voices

Contact Information:

Erica van Roosmalen

Sociology

Dalhousie University

Expenditure Term:

March 2, 1998 - August 31, 1999

Details of Expenditures:

	<u>Budget</u>	<u>Actual</u>
Salaries and benefits	\$ 7,600	\$ 7988.48
Participant honoraria	\$ 2,000	\$ 2496.00
Hospitality	\$ 200	\$ 84.20
Subcontract (transcription)	\$ 900	\$ 959.80
Travel	\$ 1,000	\$ 471.21
Office supplies and services	\$ 1,600	\$ 1487.77
Equipment	\$ 500	\$ 266.98
Conference fees & travel	\$ 1,200	\$ 1200.00
Total:	\$15,000	\$14954.44

7.0 References

Calder, B. 1977. "Focus groups and the Nature of qualitative market research" *Journal of Marketing Research* 14: 353-364.

Clancy, C.M. and C.T. Massion. 1992. "American women's health care: A patchwork quilt of gaps" *Journal of the American Medical Association* 268: 1918-1920.

Cotton, P. 1990a. "Examples abound of gaps in medical knowledge because of groups excluded from scientific study" *Journal of the American Medical Association* 263:1051-1055.

Cotton, P. 1990b. "Is there still too much extrapolation from data on middle-aged white men?" *Journal of the American Medical Association* 263: 1049-1050.

Council on Ethical and Judicial Affairs. American Medical Association. 1991. "Gender disparities in clinical decision-making" *Journal of the American Medical Association* 266: 559-562.

Denzin, N.K. 1978. The Research Act: A Theoretical introduction to Sociological Methods, New York: McGraw-Hill.

Dresser, R. 1992. "Wanted single, white male for medical research" *Hasting Centre Report* Jan-Feb: 24-29.

Gottlieb, B. 1989. A contextual perspective on stress in family care of the elderly. Canadian Psychology, 30, 3, 596-607.

Health Canada. 1999). Strategies for Population Health: Investing in the Health of Canadians. Minister of Supply and Services Canada.

Morgan, David. 1992. "Designing focus group research" In M. Stewart, F. Tudiver, M.J. Bass, E.V. Dunn and P.G. Norton (eds) *Tools for Primary Care Research* (pp. 194-208) Newbury Park, CA.: Sage Publ..

Smith, J.M. 1972. *Interviewing in Market and Social Research* Boston: Routledge and Kegan Paul.

Stewart, M., Goulet, L., Kaufert, P., Pederson, A., Pigeon, J., Poirier, L., & Ponee, D. 1997. *Report of National Discussion Group on the Determinants of Health*. Centre of excellence for Women's Health Programme.

Stewart, M., Ellerton, M., Hart, G., Mann, K., Meagher-Stewart, D., Ritchie, J. and Tomblin-Murphy, G. 1997. Insights from a nursing research program on social support. Canadian Journal of Nursing Research, 29, 3, 93-110.

Walters, Vivienne, Rhonda Lenton and Marie McKeary. 1995. Women's Health in the Context of Women's Lives Ottawa: Minister of Supply and Services.