Guiding Principles Community Consultations

A report presented to the Maritime Centre of Excellence by Susan Kirkland, Stella Lord, Pam Rubin, Jane Farquharson, Maggie Cummings, and Alison James and the Action Working Group. Report prepared by Susan Kirkland and Alison James, Researcher September 2000

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Appendices

*** These appendices are not attached but may be obtained by request from the Maritime Centre of Excellence for Women's Health.*

Acknowledgments

Executive Summary

There is increasing recognition of the importance of multi-disciplinary, multi-sectoral research in women's health. The need to link theory, research, policy development and social change in order to improve women's health dictates that individuals from government, community, clinical settings and academia must work together in an integrated fashion. However, inter-sectoral partnerships, particularly academic-community collaborations in research, face unique challenges due to social and political differences such as power dynamics, workplace value systems, and the daily realities of individuals from each sector.

The Guiding Principles Project has its roots with the inception of the Maritime Centre. Indeed, the Guiding Principles Project formed an integral part of the original proposal to Health Canada to establish the Maritime Centre of Excellence in Women's Health. The goal of the Centre is to support research, influence policy and promote action on the social factors that affect women's health and well being over the lifespan. The purpose of establishing Guiding Principles was to formulate meaningful, practical principles which can serve as a code of ethics for engaging in collaborative work, by drawing on community groups' advice and experiences. The ultimate goal is to foster an environment where individuals and organizations from community, academia, government and clinical settings who share common interests in women's health can work together in a meaningful way on a policy relevant agenda in women's health.

The Guiding Principles Project outlined in this report describes a process designed to communicate and network with community-based organizations and groups interested in women's health. The project was conducted in conducted in 3 phases.

- In Phase I, a database of 566 organizations in Atlantic Canada interested in women's health was complied, in consultation with an advisory group that included representatives from each of the four provinces; promotional materials about the Maritime Centre were developed in consultation with the MCEWH's Action Working Group.

- In Phase II, a mail-out package was sent to the 566 organizations, containing information on MCEWH, and a brief survey about the organization. Contact information and the opportunity for organizations to indicate whether they would be interested in reviewing the Centre's Guiding Principles was provided.

- In Phase III, the Guiding Principles were sent to those interested organizations for feedback. The results from the community consultations, which took the form of "kitchen table discussions" with members of the organization, were then complied and used to revise the Guiding Principles. The final version of the Guiding Principles is presented for endorsement by the Steering Committee as principles that the Centre strives to uphold and value in collaborative work.

Overall, 105 organizations responded to the mailout package sent out in phase II. Of the 105 organizations who responded, 75 organizations completed the baseline survey, which gathered profile information on the organization. Forty organizations agreed to participate in the Guiding Principles Community Consultations; sixteen organizations from all four of the Atlantic provinces completed the kitchen table consultation. Of the 16 participating organizations, 1 was classified as a health organization,

3 were women's health organizations, 8 were women's organizations and 4 were other types of community-based organizations. Overall, 3 organizations were from Newfoundland & Labrador, 3 were from PEI, 3 were from Nova Scotia and 7 were from New Brunswick. Including the pre-testing and pilot testing, a total of 70 women from 22 organizations participated in the consultations.

The Guiding Principles were generally perceived in a positive manner, however, a number of common concerns and comments were made. The feedback was related to 5 major areas:

1. Language: the language used was complicated and esoteric;
2. Terminology: the terminology required clarification and/or definitions;
3. Inclusiveness: the Principles were not completely inclusive;
4. Process: the process of how the Principles would be achieved was not stated;
5. Content: the content missed or omitted an important concept.

The strongest message arising from the participants' comments on the Guiding Principles were related to the complex language used. Several participants suggested using an Appendix to define terms and to provide examples.

Based on discussions with the research team group and a plain-language consultant, it was agreed to modify the Principles according to the rules of plain language and to make them 'stand-alone' without the necessity of an appendix. Although the use of an appendix could be used to define terms (e.g. who constitutes "diverse community groups" by listing types and target populations), ultimately groups/organizations would be unintentionally omitted and the Guiding Principles would become very cumbersome.

The editing of the third version of the Guiding Principles into the final version (version 4) was a two-step process. First, the research team used the consultations to modify the principles; secondly, a plain language consultant worked with the research team to make the principles clear, understandable, and as jargon-free as possible. We attempted to incorporate the suggestions and address the concerns from the community consultations as possible. However, it must be recognized that not all recommended changes could be made.

The Guiding Principles project has assisted in achieving the Maritime Centre's Communications and Networking Mandate, and contributed to the Centre's Knowledge Generation Mandate. The process of establishing the Guiding Principles, as well as the Principles themselves, contribute to the expanding knowledge base in participatory research and community-academic partnering. The consultation with community-based organizations will assist the Centre as it continues to develop approaches to research that are meaningful to inter-sectoral groups. The process of conducting this research project itself has demonstrated the challenging nature of completing community-based research and the realities it entails. Overall, it has demonstrated that academic and community-based researchers and organizations can work together in a productive and meaningful manner.

Guiding Principles Community Consultations

1.0 Project Summary

The Maritime Centre of Excellence for Women's Health (MCEWH) is a collaborative initiative whose goal is to support research, influence policy and promote action on the social factors that affect women's health and well being over the lifespan.

One of the first priorities of the Maritime Centre of Excellence for Women's Health has been to establish Guiding Principles, in order to provide a framework of understanding which reflects shared values. The Guiding Principles were developed in consultation with individuals from community-based organisations in the four Atlantic provinces who share an interest in women's health. The ultimate aim of this project was to foster a climate in which a policy-relevant agenda in women's health research could be undertaken.

1.1 Purpose and Research Objectives

The purpose of the Guiding Principles Community Consultation project was to establish Guiding Principles for the Maritime Centre of Excellence for Women's Health where individuals and organizations from community, academia, government and clinical settings who share common interests in women's health could work together in a meaningful way, with clearly identified common values.

Specifically, the objectives were:

(i)   To provide an opportunity for communicating with community-based organizations that have an interest in women's health, regarding the existence and aims of the Maritime Centre of Excellence for Women's Health;

(ii)   To consult with community organizations and their constituents about Guiding Principles for a Centre which values and promotes academic-community partnerships in research;

(iii)   To identify effective strategies for communication to enhance ongoing interaction with community organizations and with the women they serve;

(iv)   To develop a baseline profile of the status of community-based organizations involved in women's health in the Atlantic provinces.

1.2 Background

There is increasing recognition of the importance of multi-disciplinary, multi-sectoral research in women's health. The need to link theory, research, policy development and social change in order to improve women's health dictates that individuals from government, community, clinical settings and academia must work together in an integrated fashion. However, inter-sectoral partnerships, particularly academic-community collaborations in research, face unique challenges due to social and political differences such as power dynamics, workplace value systems, and the daily realities of individuals from each sector. Despite the fact that many case studies and

academic discussions regarding the tensions and difficulties of community-academic collaborations exist in the literature, the authors are unaware of any explicit Principles in existence.

The Guiding Principles Project has its roots with the inception of the Maritime Centre. Indeed, the Guiding Principles Project formed an integral part of the original proposal to Health Canada to establish the Maritime Centre of Excellence in Women's Health. Community consultations and the formation of Guiding Principles were proposed in response to and in recognition of the fragile but well-intentioned relationship between academic and community partners at the proposal development stage.

The Guiding Principles were originally compiled as an indication of commitment to a set of values that could be shared by all researchers, regardless of their background, with the understanding that future development of the principles would continue.

1.3 State of Current Knowledge

The term "partnership" has been used in many contexts, with differing interpretations. Though rarely defined, "partnership" implies an equality between partners, and does not recognize the differences in resources, privilege and power that different groups bring to the table. Therefore, the notion that community and academic based individuals or organizations can "partner" in research may be flawed from the outset, since equality in partnerships rarely exists. It may be more prudent to recognize that we do not enter into partnerships in a position of equality, and must actively seek equity instead.

An informative document on research partnerships examines case studies of community and academic partnerships across Canada, from a feminist perspective (Research Partnerships: A feminist approach to communities and universities working together; published by CRIAW, 1996). In each instance, the pitfalls and tradeoffs that are documented reiterate common themes. Factors identifying equitable partnerships were summarized under the headings of: goals and motivations; values, location, and limits; knowledge and expertise; equity/equality in partnerships; control and ownership; team building and mutually supportive relationships; respecting difference; mutual support; and the learning process and change. Interestingly, many partnerships are funder-driven, which poses the added strain of meeting funding deadlines, and being required to work within a framework that may not address the values of the collaborating groups.

1.4 Study Methodology

The Guiding Principles project was completed in three phases, involving community-based organizations and groups from the four Atlantic Provinces. See Figure 1 for a conceptual overview of the project.

FIGURE 1: Conceptual Overview of the Guiding Principles Consultations Project

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        ┌──────────────────────────────────────────┐
        │   Original Guiding Principles (v1)        │        Prior to Guiding
        │   Submitted in proposal to Health Canada  │        Principles
        └──────────────────────────────────────────┘        Project
              ┌──────────────────────────────────────────┐
              │  Revision of the Guiding Principles (v2)   │
              │ Completed by the MCEWH Interim Steering Committee │
              └──────────────────────────────────────────┘

  ┌─────────────────────┐        ┌─────────────────────┐
  │ Identification of   │        │ Pilot testing of    │
  │ Women's Organizations│───────│ Guiding Principles  │       Phase I
  │ and Groups n=566    │        │ (v2)                │
  └─────────────────────┘        └─────────────────────┘
                                  ┌─────────────────────┐
                                  │ Revision of Guiding │
                                  │ Principles (v3)     │
                                  └─────────────────────┘

  ┌─────────────────────┐
  │ Info Package and Survey │
  │ to Women's Organizations│                              Phase II
  │        n=566            │
  └─────────────────────┘

  ┌───────────┐   ┌─────────────────────┐
  │ Did not   │   │ Agreed to participate│             Phase III
  │ Agree     │   │ in consultation      │
  └───────────┘   │ n=40                 │
                  └─────────────────────┘

        ┌───────────┐   ┌────────────┐
        │ Response  │   │ No response│
        │ n=16      │   └────────────┘
        └───────────┘

        ┌───────────────────┐
        │ Revision of Guiding│
        │ Principles         │
        │ (v4)               │
        └───────────────────┘
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1.4.1   Phase I

Prior to the initiation of this project, a preliminary set of working Principles (version 1) were outlined in the original proposal for funding to Health Canada. These Principles were then revised (Guiding Principles version 2) and endorsed as Guiding Principles by the Maritime Centre's Interim Steering Committee.

During phase I of the project, the Guiding Principles (version 2) were pre-tested in 5 individual interviews and pilot tested in 1 focus group consisting of individuals from a targeted community-based organization, to ensure that the principles were clear enough to be understood by diverse groups. The Guiding Principles were then revised based on the feedback received (Guiding Principles version 3). See Appendix A for version 1 and 2 of the Guiding Principles.

Also during this phase, the project team worked with the MCEWH's Action Working Group to develop a brochure about the Maritime Centre, and other documents to be included in the information package mail out.

A database of 566 groups in the Atlantic Provinces involved in women's health was also complied, in consultation with an advisory group that included representatives from each of the 4 provinces.

1.4.2 Phase II

An information package was mailed out to those organizations and groups interested in women's health (n=566). The information package included the Maritime Centre brochure specifically developed as part of this project, which provided an introduction to the Centre and its mandates, described how the Centre fits into the national program in women's health, and outlined possible roles for community-based organizations to participate in Centre activities and research projects. As well, information about activities and projects of the Centre was provided.

The information package also contained a brief survey about the organization for the purpose of creating a baseline profile of women's organizations. A form for providing up-to-date contact information was provided, and organizations were asked to indicate whether or not they would like their contact information to be included in the Canadian Women's Health Network (CWHN) database or to be available to other women's groups upon request.

The women's organizations were asked to indicate whether they would be interested in reviewing the Maritime Centre's Guiding Principles with members of their organization. The Guiding Principles Consultation was described, and a reply card was provided to indicate whether or not the organization would be interested in participating. The mail-out package was provided in French for those organizations whose primary language was French. See Appendix B for the information package and the baseline questionnaire that was mailed to the organizations.

Of the 566 organizations on the mailing list, several "target groups" of organizations were identified. These "target groups" included organizations that served women who were particularly marginalized by geographic location, poverty, heterosexism, racism, and language barriers. All identified target groups with telephone contact numbers were called and encouraged to respond to the mailout and participate in the consultation.

1.4.3 Phase III

The consultation package was sent to those groups who indicated that they were interested in reviewing the draft Guiding Principles. This package contained the revised draft of the Guiding Principles (version 3), instructions for conducting a successful kitchen-table consultation, a checklist for preparing for the consultation, consent forms, and the discussion questions. See Appendix C for the Guiding Principles consultation package.

A seventy-five dollar honorarium was provided to each participating organization to be used at their discretion. The consultations were undertaken using a "kitchen table" discussion approach in which at least four women from each organization, both service providers and users, participated. One member of the group was asked to be the facilitator/record keeper. Women in the group then responded to the questions that had been pilot tested. The questions addressed both the content and format of the Guiding Principles, and also addressed ways in which communication could be enhanced and barriers to community participation in women's health research could be removed.

Contact with the organizations was by mail. The consultation involved no direct contact, but the facilitator was encouraged to call the Centre's toll-free number if they had any questions or concerns. A follow-up reminder letter was sent (via email, fax, or mail) in February 2000 to all organizations who had agreed to participate. Once the organizations had completed the kitchen table discussions, they were asked to return their responses by mail to the Maritime Centre.

The results of the kitchen table consultations were then compiled and used by the project team to revise the Guiding Principles. As well, the information gathered in the initial survey was entered into a database. Updated contact information, as well as a list of groups who wished to be part of the Canadian Women's Health Network (CWHN) database and other mailing lists was compiled and given to the MCEWH information officer.

The Guiding Principles that were reviewed by community-based organizations are as follows:

Principle #1: We will link policy, action and research by bringing together women from diverse community groups, different fields of university and community-based research, and various sectors of government to work together on the framework, organization and priorities of the Centre in a collaborative and representative way.

Principle #2: We will take a woman-centred approach to research by including women from diverse racial, cultural and economic backgrounds and geographic locations in an equitable and representative way in the development of the Centre's priorities and in collaborative research projects.

Principle #3: We will acknowledge, respect and value the unique knowledge, expertise and contributions of all women involved in the Centre, and their input will be included in decision-making processes.

Principle #4: We will encourage research which is conducted in co-operation with community-based organizations. Researchers, whether university or community-based, will work together with women from the community to set priorities for research.

Principle #5: We will also encourage participatory research which involves women from the community in all aspects of the research and especially in determining what issues will be researched and what research methods will be used.

Principle #6: We will encourage research which considers factors not always taken into account in women's health research and which takes a holistic approach. Holistic research involves looking at various factors in women's physical, social and economic environments which influence their health. These may include, but are not limited to, racism, poverty, homophobia, sexism, and geographic location.

1.5 Partnership Development

The research team for this project involved both community and academic based researchers. As well, the research team worked closely with the Maritime Centre's Action Working Group in the early development of the project, and with Steering Committee members to identify organizations involved in women's health across the Atlantic provinces.

Through the Guiding Principles Community Consultations project we initiated contact with a range of community-based organizations throughout the Atlantic Provinces, most of whom have never participated in a MCEWH research project. The Centre was promoted to over 500 organizations by mailing the MCEWH promotional materials. The organizations who provided their updated contact information and expressed an interest in the distribution of their contact information and/or have participated in the baseline questionnaire may choose to engage in future collaborations with the Maritime Centre and/or like minded organizations, as a direct result of their involvement with this project. With the information on preferred mechanisms of communication, the Centre will be in a better position to network with organizations in its community, and increase the potential of developing future collaborations. Furthermore, the Guiding Principle consultation process has initiated the development of a relationship that can be

meaningful to both community-based and academic groups. It has also demonstrated the Maritime Centre's commitment to future cooperation, collaboration and partnering between academic and community groups interested in women's health.

1.6 Final Results

The results of the Guiding Principles project are presented in 3 sections: (a) provision of up-dated contact information and interest in distribution of contact information (b) a description of baseline characteristics of Women's Organizations; and (c) the feedback from the Guiding Principles Consultations.

1.6.1 Contact Information

Of the 566 information packages mailed out to community organizations and groups interested in women's health, 105 organizations (19%) responded in some manner, completing either the reply card and/or the mailing list information. The updated contact information for the participating organizations (n=101) was provided to the MCEWH information officer. Four organizations sent back their reply cards with no contact information.

The majority of the respondents did not want to be included on database distribution lists. Thirty of the responding organizations (29%) wished to be included in the Canadian Women's Health Network database compared to 69 organizations (66%) who did not want their contact information to be included in the database. There was missing information for 6 organizations. Overall, 32 organizations (30%) were interested in the Centre in distributing their contact information, and 67 organizations (64%) did not want their contact information to be distributed (there was missing information for 6 organizations). The list of respondents, sorted by their interest in being included in the database distribution lists, were forwarded to the MCEWH information officer.

Of the 105 respondents, 4 organizations indicated that they did not wish to remain on the Centre's mailing list and 14 organizations had missing information. Again, the list of respondents sorted by their interest in remaining on the Centre's mailing list is provided to the Maritime Centre.

1.6.2 Baseline Characteristics of Women's Organizations

A total 75 community organizations/groups participated in the baseline profile survey which represents a 13% response rate based on all organizations contacted (n=566); and a 71% response rate based on those organizations that completed either the contact information and/or the reply card (n=105). The following section summarizes the characteristics of responding organizations interested in women's health. It should be noted that the descriptions are only reflective of the participating organizations which may or may not be reflective of those organizations that did not participate in the survey.

The majority of the respondent organizations were from Nova Scotia (50%), followed by New Brunswick at 30%. Organizations in Prince Edward Island and Newfoundland and Labrador comprised 12% and 8% of responses respectively (see Figure 2).

**FIGURE 2: Responding Women's/Health Organizations
by Province (n=74)**

NF & LAB
8%

NB
30%

NS
50%

PEI
12%
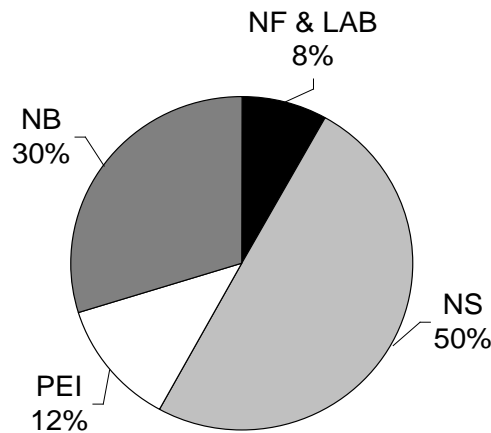
## 1.6.2.1 Characteristics of Organizations and the Clientele/Members They Serve

Participating organizations were classified according to the primary characteristics or emphasis of the organization. Of the 75 responding organizations, 40% were from women's organizations, 19% were from health organizations, 15% were from family-based organizations, 5% were from women's health organizations, and 21% were from other types of community based organizations (see Figure 3).

**FIGURE 3: Respondents by Type of Organization They
Represent (n=75)**

Women's
Health Org.
5%

Other types of
Org.
21%

General
Health Org.
19%

Family Based
Org.
15%

Women's Org.
40%
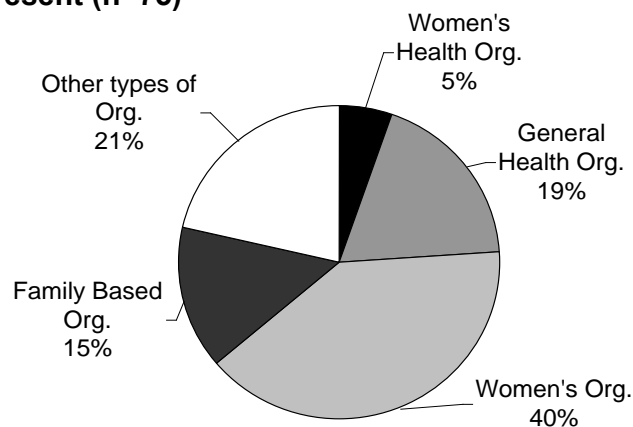
The majority of responding organizations (66%) indicated that 81-100% of their clientele/members were women. In comparison, only 1% of the respondents had clientele/members who constituted 0-20% women. Figure 4 depicts the percentage of organizations whose members were women.

FIGURE 4: Percentage of Organizations Whose Clientele/ Members Are Women (n=72 organizations)
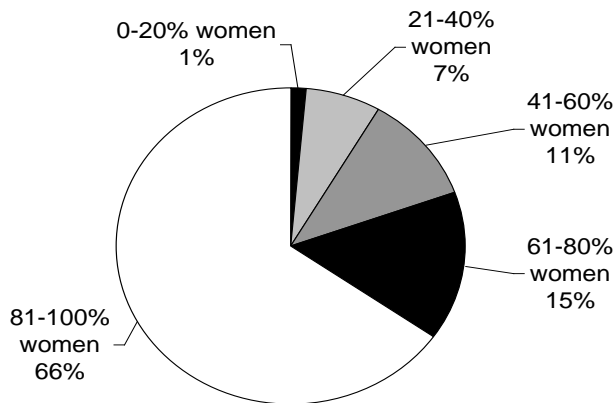
Seventy-five percent of the respondent's female clientele/memberships belong to the 21-40 year old age group, followed by 40% belonging to the 41-60 years old age group. See Figure 5 for the percentage of organizations that serve the 0-20, 21-40, 41-60, 61-80 and 80+ age groups.

FIGURE 5: Age Groups that Women's/Health Organizations Serve (n=72 organizations)
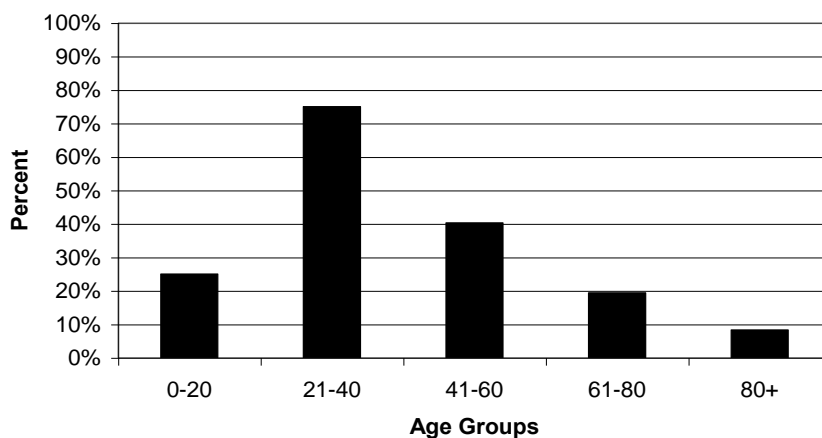
**1.6.2.2 Services and Programs Provided by Organizations**

The 3 most common services provided by the responding organizations were information and resources (89%), education (78%) and referrals (68%). Between 40-60% of the organizations provided advocacy (58%), counselling (49%), skills training (46%) and political advocacy (44%). Only 35% and 14% of the responding organizations provided accompaniment and shelter respectively. See Figure 6 for the services provided the responding organizations.

FIGURE 6: Services Provided by Women's/Health Organizations (n=72 organizations)
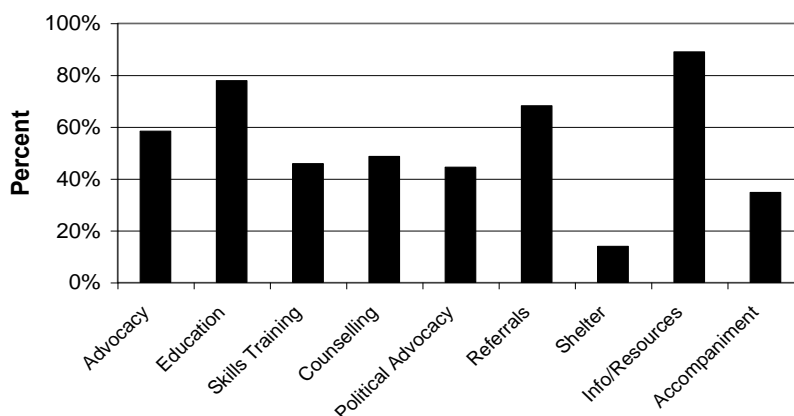
The baseline survey also provided the opportunity for the participating organizations to indicate other services that they provide. The most frequently identified services provided were social support (n=9), child care (n=6), health/clinical services (n=6), community/policy development (n=5), and poverty relief including the provision of food and clothing (n=4). Programs designed specifically for women were offered by 69% of participating organizations. Table 1 shows the most commonly identified types of programs offered, and they are presented in descending order according to how often they were identified. The most prevalent program topics were related to general health and mental health.

Table 1: Most commonly identified programs offered specifically for women

	Program Topic	Examples	Frequency
1	Health related program	Smoking cessation, menopause, heart smart, breast exams, general health information, sexual health counselling, eating disorders	15
2	Mental health	Self-esteem, empowerment, support, spirituality, anger management, body image	12
3	Employment Training	Resume writing, professional development, facilitator training, communication	8
4	Specific counselling/therapy	Survivors of sexual abuse, women who have been abused	7
5	Family/Parent support and education	Prenatal nutrition, mothers support groups, Healthy Baby Club, childcare, breast feeding support	5

6	Recreation Programs	Craft classes, fitness program, yoga, canoeing	4
7	Self defense and violence related	"Take back the Night", date rape awareness	3
8	Income aid	Community kitchens, poverty & economic development	2
9	General women's workshops, lectures	International Women's Day, media releases	2

1.6.2.3 Administrative Characteristics of Organizations

Of the 69 organizations that answered the question relating the budget, 42% had a budget of more than $150,000 and 17% had a budget of less than $25,000. Figure 7 depicts the percent of organizations falling into each of the budget categories.

FIGURE 7: Budget Categories for Women's/Health Organizations in the Last Fiscal Year (n=69 organizations)
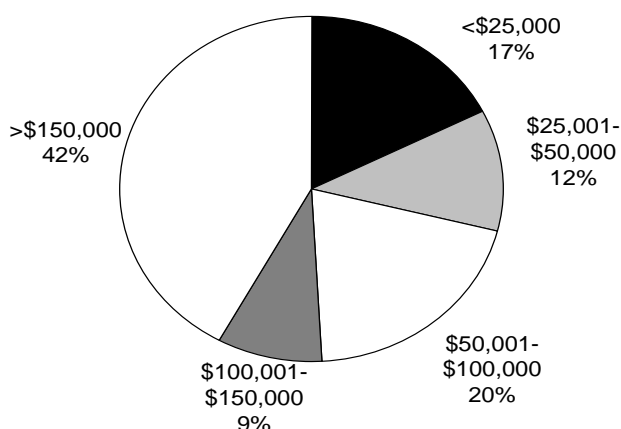
Sixty-six percent of responding organizations were run by staff and volunteers, while 21% were run by staff alone and 13% were run by volunteers only (see Figure 8). The organizations currently employed on average 6.1 full-time and 2.5 part-time employees. The range of full-time and part-time employees ranged considerably from 0 to 111 and 0 to 17, respectively.

In the survey, the participants were asked to comment on the major challenges that their organization faced over the past three years. The majority of the challenges were related to financial and human resources. Table 2 provides a list of commonly identified challenges.

**FIGURE 8: Percent of Women's/Health Organizations
Run by Staff, Volunteers or Both (n=75 organizations)**

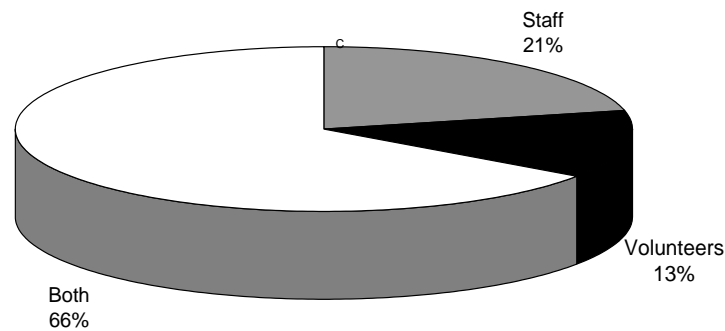
Staff
21%

c

Volunteers
13%

Both
66%

Table 2: Commonly Identified Challenges

1. Lack of financial resources/fiscal management.
2. Lack of human resources.
3. The needs exerted on the organization are greater than the resources available.
4. Unstable funding and lack of security for funding.
5. Lack of promotion of the organization and the services it provides.
6. Lack of strategic planning, organization and the effects of downsizing.
7. Lack of sustainability.
8. Community has limited access to services and organization has difficulty in reaching the target population.
9. Matching programs to the needs of the community.

1.6.3 Guiding Principles Consultations

1.6.3.1 Description of the Participating Organizations

Of the 75 organizations that participated in the Survey of Women's Organizations in Atlantic Canada, 40 agreed to participate in the Guiding Principle Consultations. Sixteen organizations completed the consultation, 4 subsequently declined via personal communication after the follow-up reminder letter, and there was no further response from 20 organizations. Overall, the response rate was 40%.

Of the 16 participating organizations, 1 was classified as a health organization, 3 were women's health organizations, 8 were women's organizations and 4 were other types of community-based organizations. Overall, 3 organizations were from Newfoundland & Labrador, 3 were from PEI, 3 were from Nova Scotia and 7 were from New Brunswick. Including the pre-testing and pilot testing, a total of 70 women from 22 organizations participated in the consultations.

1.6.3.2   Guiding Principles Consultations – "Kitchen Table Talks"

The results from Guiding Principles Consultations will first be summarized according to agreement with each of the six Principles. Then, the comments on Principles will be summarized thematically. Quotes from 'kitchen tables' talks will be provided to give a context to the issues and comments raised. Based on the consultations, the modified Guiding Principles will then be presented. Finally, the relationships between researchers and community-based organizations will be examined for ways to promote communication and create more effective partnerships in conducting women's health research.

Overall, the participating groups agreed with the Principles and they were received in a positive manner. Agreement with the Principles will be presented in descending order, with the Principles with the greatest agreement presented first. All of the participant groups agreed with Principle #1 and #3 (16/16) and those participants that responded to Principle #6 all agreed with it (15/16, 1 no response). One and two organizations did not agree with Principle #2 (15/16 agreed) and Principle #4 (14/16 agreed) respectively. For Principle #5, 13 agreed with it, 1 participating organizations did not agree with it, and 3 had questions regarding the Principle and did not explicitly state whether they agreed with the Principle or not.

Appendix D provides the consultation summary results by each question outlined in the 'kitchen talk talks' guidelines. However, for the purposes of this report, the feedback from the Guiding Principles consultations will be summarized by the following 5 themes.

1. The Language Used

A very prominent theme from the remarks on the Guiding Principles was that language used was complicated and esoteric. For example, one organization suggested that the statement "…priorities of the centre in a collaborative and representative way" in Principle #1 was not expressed concretely. Below is a list of some of the participants' specific comments relating to the language used in the Principles:

> … the principle itself is hard to know or to understand, just what exactly it means. We found the jargon used was confusing and perhaps wording should be made simpler for all to understand. All education levels have to be considered if the expectation is that all women are to understand and comment on these principles...

> … all principles should be re-worded in plain language at a level of sophistication open to all women….Language is academic and global.

> The statement (Principle #2) should more like government language – it needs to be stated in plain language – if not, there is an automatic alienation of many women who will not understand the statement.

> It (Principle #1) is too wordy and needs to be reframed in a more 'understandable' way (especially important for those with low literacy). We suggest 'We will link policy, action, and research by bringing women together to work on framework, organization, and priorities of the Centre.

2. Term Clarifications and Definitions

Resulting from the complex language used, clarifications or definitions of numerous terms used in the Principles were requested. The suggested terms that needed clarification or definitions included "action", "diverse community groups", "fields of University", "various sectors of the government", "equitable", "representative", "collaborative", Woman-centred approach", "community based organizations", "participatory research", and "holistic". These words provided a starting point to address how the Guiding Principles should be modified so that the language is more understandable.

3. Inclusiveness

Several participants were concerned with the inclusiveness of the Principles, especially when a list of examples were provided. Specifically, there was concern with Principle #2 with regards to who constitutes 'diverse women'. The suggested additions included women from 'diverse health issues', 'diverse educational backgrounds', 'sexual diversity', 'diverse ability' and 'diverse age'. Although 'geographic location' was stated in Principle #2, two organizations thought it needed greater emphasis because of the historical under-representation of rural areas.

> …Geographic location needs to be re-stated. Will rural areas be clumped with urban areas and will our input be valued?.

> … Special concern should be given to geographic aresa that have been under-represented in the past.

The participants had vastly different opinions on how to modify Principle #6. While some participants felt that the Principle did not need the definition or examples of holistic research, others requested to expand the definition and examples of holistic research. The list of terms suggested for expanding the definition of holistic research, along with the frequency that they were mentioned are as follows: spirituality (x3), emotional (x4), psychological (x2), demographic factors (e.g. age (x2), and martial status (x1)), and intellectual (x1).

> …We'd also like to see spirituality included specifically, and some mention might be made of the psychological environment of women's health.

> Women in the group discussed the connection between physical- mental-emotional health. Their experience is that emotional content 'turns off' many in the health profession.

Of those participants that requested further examples of holistic research, all of their comments pertained to the addition of physical/mental abuse (x2) or violence (x2).

> Agreed, but felt that we need to include physical and mental abuse. We know that violence is systemic in our society and it affects women's health in many subtle ways.

Given the reality of interpersonal-intrapersonal violence/abuse and ritual abuse-torture, its impact on all of women's health, it is a glaring omission not to include this in the list of racism, etc.

4. The Process – How the Principle Would Be Achieved

A number of the participants questioned how each one of the Principles would be achieved. Table 3 provides the specific comments related to the each of the Principles.

Table 3: Participants comments relating to how the Principles would be achieved

Principle	Comment
#1	"The consensus was – the group agreed with the principles but questioned how it would actually be achieved".
	"Yes, with classification of the process of how to bring women together".
	"Would be important to ensure the ratio of groups to be fairly distributed. Question: how are you going to invite participatory involvement?"
	"How and where will these women be brought together? In order to do this time frames must be realistic. It is difficult to get rural women together without sufficient notice…"
#2	"Yes, although we would like you to be specific as to how you will do this".
#3	"How is this accomplished? How are decisions reached".
	"Question: How do you include all the diversities and minorities".
#4	"Again, how will you do this? Will you advertise for input from groups, make presentations to women's groups, request proposals, etc"
	"Yes, but how is this financed, small communities have no financial resources to pay for professional research. This has to be addressed".
#5	"How will this be done? How will the safety and protection of women who participate be guaranteed"?

5. Content

The participating groups were asked if there were Principles that they thought were important, which were not covered. Additional Principles were requested relating to how the Centre would be accountable and how they would evaluate their success in achieving the Principles.

> Principles #7: We will ensure that research is accountable via an ethical committee, review process, which is transparent.

> … how will MCEWH evaluate their own success in achieving their Principles.

… ensure diversity in the decision making role of who gets research money as opposed to just ensuring diversity within the research projects.

Other participants thought that there should be a Principle on how the Centre would translate their research initiatives into promoting action and influencing social policy. The specific comments were as follows:

… how will these research initiatives translate action and influence social policy as mentioned in the Centre's goals?

There would need to be principles relating to promoting social change other than through research and perhaps have some reflecting a philosophy of communication with people in the community. What principles are in place to govern 'policy advise'?

While the principles demonstrate a desire to examine and understand, we would like to see more commitment to acting on gaps, problems, etc in research findings.

Some of the participants also requested content clarification for several of the Principles. Others expressed additional ideas to be incorporated into several of the Principles. Table 4 provides the specific comments related to each of the Principles.

Table 4: General comments about the Guiding Principles

Principle	Comments
#1	"We feel that Guiding Principle #1 is a bit broad and could be more clearly defined using aims" "You might want to consider re-ordering your principles. Start with the ones regarding respect and value and move into bigger, broader ones".
#2	"Yes- although the wording makes the meaning unclear. Is the purpose of this principle to prioritize by consulting women from diverse backgrounds and sectors or is the intent to recognize the diversity of women's needs/assets in establishing priorities". "We would like the priorities itemized and some idea on who contributed to the centre".
#3	"It was agreed that our group would like to see added next to unique experiences and personal knowledge". "Would suggest additional wording be added …their input will be included in transparent and accountable decision-making processes with feedback mechanisms in place".
#5	"Agreed, our group felt that this was a great principle. Community women need to be involved in all aspects of research". "...most average people do not understand research methodology very well… Do women in the community want this kind of responsibility" Are they capable of

	determining issues and methods of research"?
	"…what issues will be researched and what methods will be used? Who will be responsible for monitoring what research is carried out at the Centre? Who will be encouraged to participate as research subjects"?
	"Yes, provided this is backed up with training, so that both women from the community and women from the university community approach the table on an even playing field".

1.6.3.3 Guiding Principles Final Version

The strongest message arising from the participants' comments on the Guiding Principles were related to the complex language used. Several participants suggested using an Appendix to define terms and to provide examples.

Based on discussions with the research team group and a plain-language consultant, it was agreed to modify the Principles according to the rules of plain language and to make them 'stand-alone' without the necessity of an appendix. Although the use of an appendix could be used to define terms (e.g. who constitutes "diverse community groups" by listing types and target populations), ultimately groups/organizations would be unintentionally omitted and the Guiding Principles would become very cumbersome.

The editing of the 3rd version of the Guiding Principles into the final version (version 4) was a two-step process. First, the research team used the consultations to modify the principles; secondly, a plain language consultant worked with the research team to make the principles clear, understandable, and as jargon-free as possible. We attempted to incorporate the suggestions and address the concerns from the community consultations as possible. However, it must be recognized that not all recommended changes could not be made.

The goal of the Maritime Centre of Excellence for Women's Health is to support research, influence policy and promote action on the social factors that affect women's health and well-being over their lifespan. We do this by bringing together:

- Women from community groups and communities of interest;
- Researchers based in universities, health care settings and communities; and
- Policy-makers from all sectors.

Our decisions and activities will be guided by the following principles:

Principle: Inclusiveness and Diversity
We welcome all women and value their contributions to the work of the Centre. We will continue to work to include the viewpoints of women of all ages and abilities from diverse racial, cultural, socio-economic and educational backgrounds who live in all parts of the Atlantic region.

Principle: Mutual Respect
We acknowledge and respect the unique experience, perspective, knowledge and expertise that each woman brings to the Centre. We will respect one another and work together in ways that recognize that all contributions are of equal importance and all persons of equal value.

Principle: Fairness
We will work with women in communities, women's groups, community and voluntary organizations, researchers and policy-makers to find ways to ensure that all voices are represented fairly.

Principle: Woman-Centred Research
We support research that addresses the factors affecting women's health and well-being over their lifespan and is:

- **Holistic**: Holistic research integrates a broad range of physical, emotional, spiritual, social, economic and environmental perspectives into our understanding of women's health. These can include factors not always taken into account in health research -- for example, racism, poverty, sexism, violence and geographic isolation.
- **Cooperative, Collaborative and Participatory:** We will encourage research that involves women from the community in making decisions about all aspects of the research. Women from the community will be respected as active participants and not confined to the role of "research subject." Researchers will work with the community to determine what issues will be researched and to set priorities for research. Women and researchers will work together to decide what research methods will be used, what the research findings mean and how the findings will be used and communicated.

Principle: Accountability
We will be accountable for basing our decisions on these principles and will develop mechanisms for monitoring research to ensure that it reflects these principles. We will develop decision-making processes that are transparent and accountable and include ways for interested parties to offer comments and feedback.

The Maritime Centre of Excellence for Women's Health (MCEWH) is one of five national Centres of Excellence established to direct attention to women's health concerns and to promote research on women's health. We are supported by Health Canada through the Women's Health Bureau.

1.6.3.4 Communication and Partnering for Women's Health Research

In the 'kitchen-tables talk' guidelines, the participants were also asked to address the relationship between community-based organizations and researchers in doing women's health research. The participants were first asked how the Principles could be used to help promote academic-community partnerships in research. In general, the suggestions fell into 2 categories- either they were related to proposals and review or they were related to networking and communication.

The following recommendations were made in regards to how the Principles could be used for process of writing and reviewing research proposals:

- Send Requests for Proposals (RFP) to community groups.
- Balance the review panels between community groups and academics.
- Promote partnerships by ensuring that participation from academic and community-based groups is a primary goal of approved research projects.
- Requests for proposals should include specific criteria to ensure the Principles are adhered to.
- Funding for research should be based on the Principles.
- Ethical review would ensure accountability, prevent abuses of the process, protect vulnerable persons/groups and promote feedback loops.

A number of suggestions related to how the Principles could be used to enhance networking and communication between community groups and academics were made; they are as follows:

- Networking workshops to bridge the gap between academics and the community.
- Create a database of groups useful for researchers who are often in search of community participants.
- Link various groups together on a geographic basis.
- MCEWH should have representatives in regions throughout the Atlantic Provinces.
- Easy access for the population to reach MCEWH (web site, toll free number).
- Encourage universities to involve themselves in community research.
- Have available researchers willing to be consulted by community groups wishing to do their own research.

On the basis of their experience, participants identified those factors that lead to successful or unsuccessful projects when conducted with other organizations. Table 5 provides a list of factors that lead to successful or unsuccessful projects.

The participants were invited to identify ways that their organizations could benefit or contribute to Maritime Centre. One of participating organizations had never heard of Centre before the Guiding Principles Community Consultations and greater marketing of the Centre was suggested.

The panel all said they had never heard o the Centre until they were approached to take part in the survey

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Table 5: Factors that contributed to successful or unsuccessful projects

Factor that contributed to successful projects	Factors that contributed to unsuccessful projects
• Respect • Co-operation • Open communication • All stakeholders involved • Commitment • Supportiveness • Common goals • Defined purpose/plan • Similar values • Sharing of resources • Group free from outside financial control	• Lack of communication • Lack of consideration/open mind • Lack of participation • Hidden/own agenda • Lack of respect • Lack of plan/purpose/direction • Obligations and restraints (political/financial) • Coordination of schedules • Being a "token" person in the group • Too academic • Lack of defined roles • Competition for funding

Another organization was unclear what the Centre actually does.

> … We do need a clearer picture of what you can provide to and for us. What is available for us- financially and information wise? What types of projects are you considering? How do we bring research projects to your attention …

Ways in which community organizations felt they could benefit from the Maritime Centre included:

• consultation and collaboration
• information on research projects
• information on research findings and information materials
• support and networking (financial and otherwise)
• assist in creating social change
• assist community groups identify potential research projects
• topic specific research

Ways in which community organizations felt they could contribute to the Centre included:

• Promote awareness of the MCEWH and of women's health issues
• Provide members an opportunity to be involved in research projects
• Allowing the Centre to use the experiences and research of community organizations.

One participant did not explicitly state the ways that their organizations could benefit or contribute to/from the Centre. Instead, they emphasized the importance of developing a symbiotic relationship.

That depends on what we as an organization and the MCEWH can gain in terms of support for each other and how priorities are set.

To develop relationships between the Maritime Centre and community-based organizations, several participants suggested that the Centre provide representation at the community level or allow community organizations to become Centre members.

Need representation- cannot put actual feelings expressed at focus group on paper. Need a direct link.

2.0 Schedule of Activities

All of the original objectives for the Guiding Principles Consultation Project were met, however the initial time line for completing this project had to be extended for several reasons. Firstly, the original list of 644 community-based organizations had to be significantly revised, as many of the groups on the initial list were strictly government or academic organizations. As well, the information on the initial list had become outdated, and the contact information for the 566 groups that remained on the list had to be checked for accuracy and revised. This process was time-consuming and on going.

Secondly, the project team was concerned that the language used in the draft Guiding Principles (version 2) was too "jargon-y", and might not be well received by the consultation participants. In order to avoid this possible pitfall, five individuals representing various community-based organizations were asked to review and suggest changes to the Principles. The Principles (version 2) and kitchen table questions were also pilot tested with a group of individuals from a local women's organization. A great deal of feedback was generated from these discussions, and it was evident that the Principles did need revision before they could be sent out for general viewing. The Guiding Principles were modified again (into version 3) by incorporating these suggestions. This process was essential but also very time consuming.

A number of practical difficulties were encountered in conducting the baseline survey and the consultations with community-based organizations. The turn-around time for the initial mailout was much slower than anticipated and the overall response rate to the project was much lower than what was expected. It was anticipated that 100 organizations would participate in the Guiding Principles consultations. In actuality, only 105 organizations responded to the mailout, only 75 took part in the baseline survey, only 40 agreed to participate in the Guiding Principles consultation and only 16 organizations actually completed the consultations. Many community-based organizations face time, human resource and financial challenges, which may have influenced their ability and/or their willingness to participate in such a process. Given the reality of these problems, extending the turn-around period for project was very important to the success of the project. In addition, many of the organizations in the target groups took much longer to respond to the mailout than other organizations because of their resource constraints. Theses groups were of particular importance to the Guiding Principles Consultations for these very reasons, and allowing extra turn-around time for them was imperative.

3.0 Dissemination Plan

One of the original purposes of this consultation project was to develop a set of Guiding Principles that the Maritime Centre of Excellence for Women's Health would then adopt to monitor and evaluate all activities of the Centre. Therefore, the Guiding Principles will first be presented to the Steering Committee of the Maritime Centre for adoption and they will subsequently be disseminated to all members of the MCEWH. If adopted, the Principles will act as a set of research guidelines and will accompany all research proposal applications. All organizations that participated in the consultations will also receive a copy of the revised Guiding Principles (version 4) and a copy of the final report, if it was requested.

The preliminary results of this project have already been presented at two conferences held by the MCEWH in Halifax, Nova Scotia. The final report will be available on the Centre's web-site and it will be presented at the Centre's 'Lunch N Learn' series, which is open to all individuals interested in women's health. In addition, the project is being presented in a edited document of work, under development by the Maritime Centre. If the Centre receives requests for contact information from other organizations interested in women's health, this updated information can be provided along with the organizations' associated baseline characteristics. Such dissemination of contact information can enhance the communication and interactions between other community organizations. In addition, the process of conducting the Guiding Principles project has provided the opportunity for disseminating the Maritime Centre's promotional materials.

4.0 Implications for MCEWH Mandates and Research Programs

The Guiding Principles project has assisted in achieving the Maritime Centre's Communications and Networking Mandate, with a contribution to the Centre's Knowledge Generation Mandate. This project has provided the opportunity for communication and interaction between the Maritime Centre and community-based organizations that have diverse purposes, levels of funding and that are from diverse geographic locations. The collection of the updated mailing list information and the database distribution lists assists in building and strengthening local and national networks of individuals, institutions, and organizations involved in women's health. The baseline survey provided a context of the organizations interested in women's health in Atlantic Canada. The process of establishing the Guiding Principles, as well as the Principles themselves, contribute to the expanding knowledge base in participatory research and community-academic partnering.

This consultation with community-based organizations will assist the Centre as it continues to develop approaches to research that are meaningful to inter-sectoral groups. The participants for the Guiding Principles consultations were diverse in their knowledge and their experiences, which is one of the Centre's strategies in building its Communications and Networking Mandate.

The process of conducting this research project itself has demonstrated the difficult nature of completing community-based research and the realities it entails. For example, the resource constraints faced by many organizations can lead to poor participation and create slow turn-around periods for research projects. The financial and human resource challenges encountered by community-based organizations must be considered when planning and conducting inter-

sectoral research. Overall, it has demonstrated that academic and community-based researchers and organizations can work together in productive manner.

5.0 Impact on Policy-Making

To achieve the Maritime Centre's goal of supporting research, influencing policy and promoting action on the social factors that affect women's health and well being over the lifespan, it is necessary to use a multi-disciplinary, multi-sectoral approach. However, inter-sectoral partnerships, especially academic-community collaborations, face many challenges. The primary objective of conducting the Guiding Principles Project was to establish meaningful principles for engaging in collaborative work with individuals and organizations from community, academic, government and clinical settings. It is recommended that the Centre adopt the Guiding Principles (version 4) and use them to monitor and evaluate all activities of the Centre. The Principles should also be used as a set of research guidelines and should accompany all research proposal applications. The participants also suggested that the Centre should develop a transparent and accountable decision-making process that includes ways for interested parties to offer their feedback. Our results from the Guiding Principles suggest that all literature from the Centre should be written according to the principles of plain language. With respect to conducting research with community-based organizations, our experience suggests that adequate time must be given for conducting collaborative research projects.

Appendix A: Guiding Principles (Versions 1 & 2)

Guiding Principles Version 1
(From original proposal to Health Canada)

A woman-centred approach that validates women's perspectives and experiences would link research, policy and action activities of the Centre.

Participatory action research methods would be used wherever possible. Participatory research occurs in different ways depending on the specific methodological requirements of the project.

Contextual research that acknowledges the influences of the environment on women's women's lives, their health, health behaviours and health services use, would be encouraged.

Project teams and working groups would be interdisciplinary, intersectoral and linked to the community. The teams would include women from the community who will help to determine the variables of interest and representatives of community based organizations who would help to set priorities.

Participants in the research, information, communication, networking and policy advice work of the Centre would strive for excellence.

The unique knowledge, expertise, contributions and responsibilities of community groups, women, researchers, practitioners and policy makers participating in the Centre's work would be respected.

Guiding Principles Version 2
(After changes made from the Interim Steering Committee)

1. A woman-centred approach that validates women's perspectives and experiences will link research, policy, and action activities of the Centre.

2. Participatory action research methods will be used wherever possible. Participatory research occurs in different ways depending on the specific methodological requirements of the project.

3. Contextual research that acknowledges the influence of the environment on women's lives, their health, health behaviours and health services use, will be encouraged.

4. Project teams and working groups will be interdisciplinary, intersectoral, and linked to the community. The teams will include women from the community who will help to determine the variables of interest and representatives of community-based organizations who will help to set priorities.

5. Participants in the research, information, communication, networking and policy advice work of the Centre will strive for excellence.

6. The unique knowledge, expertise, contributions and responsibilities of community groups, women, researchers, practitioners and policy makers participating in the work of the Centre will be respected.

7. The organization, framework and priorities of the Centre will be determined in a collaborative and representative way.

Appendix E: Policy and Research Fact Sheets

Guiding Principles Community Consultations: Policy Fact Sheet

Principal Investigators: Kirkland SA, James AD
Contact: Susan Kirkland Community Health & Epidemiology, Dalhousie University
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Major Finding #1: A set of principles were developed to guide community and academic involvement in women's health research. The themes that the Guiding Principles represent include: • *Inclusiveness and diversity*: The Centre will welcome and value the contributions of all women. • *Mutual respect*: Respect of the contributions that each woman brings to the Centre. • *Fairness*: To ensure that all voices from women in the community, researchers and policy-makers are represented fairly • *Woman-centred research*: Research that is holistic, and participatory, cooperative and collaborative. • *Accountability*: To ensure that the Centre is accountable for living up to these Guiding Principles.	**Policy/Program Implications with Major Finding #1:** (a) It is recommended that the Centre adopt the Guiding Principles to monitor and evaluate all activities of the Centre. (b) It is recommended that the Guiding Principles be used as a set of research guidelines and that they accompany all research proposal applications.
Major Finding #2: The participants in the consultations emphasized that the Guiding Principles should be written according to the rules of plain-language.	**Policy/Program Implications with Major Finding #2**: (a)All literature from the Centre should be written according to the principles of plain language.
Major Finding #3: The participants suggested that Centre should be accountable for living up to the Guiding Principles.	**Policy/Program Implications with Major Finding #3:** (a) The Centre should be accountable for developing and implementing their programs and policies according to the Guiding Principles. (b) The Centre should be develop a transparent and accountable decision-making process that include ways for interested parties to offer their feedback.

Guiding Principles Community Consultations: Research Fact Sheet

Principal Investigators: Kirkland SA, James AD
Contact Name: Susan Kirkland Community Health & Epidemiology, Dalhousie University
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Research Finding #1:

A set of principles were developed to guide community and academic involvement in women's health research. The themes that the Guiding Principles represent include:
- *Inclusiveness and diversity*: The Centre will welcome and value the contributions of all women.
- *Mutual respect*: Respect of the contributions that each woman brings to the Centre.
- *Fairness*: To ensure that all voices from women in the community, researchers and policy-makers are represented fairly
- *Woman-centred research*: Research that is holistic, and participatory, cooperative and collaborative.
- *Accountability*: To ensure that the Centre is accountable for living up to these Guiding Principles.

Research Finding #2:

The participants in the consultations emphasized that the Guiding Principles should be written according to the rules of plain-language.

Research Finding #3:

The participants suggested that Centre should be accountable for living up to the Guiding Principles.

Recommendations:

1. The Guiding Principles should be adopted by the Maritime Centre of Excellence for Women's health and used in the development and implementation of their programs and policies.
2. All literature from the Centre should be written according to the principles of plain language. The Centre should continue their effort in providing the opportunities for community-based organizations and researchers to work together in manner that is meaningful and relevant to all parities involved.