

## **Shaping Women's Health Research: Scope and Methodologies**

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The best cases used in this paper are examples only, and do not mean to imply that there is not other work being done that is as good or better. If you have best case examples to share, or other comments, please contact the author at <criaw@sympatico.ca> or at Canadian Research Institute for the Advancement of Women (408 - 151 Slater Street, Ottawa, Ontario, K1P 5H3).

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## **EXECUTIVE SUMMARY**

This paper reviews important issues pertaining to women's health research questions, design, ethical reviews, analysis, presentation and dissemination of results, and the possibilities for resulting action and policy changes. It examines power and perspective in feminist participatory action research, and presents best cases and gender analysis tools for women's health research. The paper briefly looks at the current women's health research environment, the emerging Canadian Institutes of Health Research (CIHR), and the ongoing problem of the dearth of meaningful research for lesbians, Aboriginal women, women of racial, ethnic and linguistic minority backgrounds, women with disabilities, young women, and women over 65. The paper makes recommendations on each of these issues.

## **RESEARCH FINDINGS**

- Even in health research done by and for women, there are imbalances in power and perspective. There are major health research gaps, particularly their priorities and needs, for lesbians, First Nations, Inuit and Metis women, women of ethnic, racial and linguistic minorities, and women with disabilities.
- To date the emerging CIHR shows no signs of gender analysis or of building on what we know about women's health research, determinants of health, and participatory action methodologies.
- Women's health research findings are not adequately communicated to women, particularly those who are low-income, Aboriginal, members of ethnic, racial or linguistic minorities, and with disabilities.
- There is a huge and increasing gap between health determinants research results and recommendations and government policy on income support and other social and economic policies.
- Not all the recommendations of the 1995 National Symposium Women in Partnership: Working Towards Inclusive, Gender-sensitive Health Policies have been implemented.

## **POLICY IMPLICATIONS**

- The Centres of Excellence and other agencies should seek out and support members of these communities to engage in participatory action health research. Funding agencies should encourage team research with members reflecting the diversity of the research population; establish research partnerships with community organizations; perform community-based research; and pilot the research with participants and use their feedback to make the research design more effective. Women's health researchers and agencies should work to ensure this policy direction is understood and adopted by mainstream health research funding agencies.
- A cross-Canada network of women's health researchers should be formed to work with the Gender and Women's Health Research Working Group on the CIHR, to lobby for gender parity on the CIHR Governing Council, to educate Council members on women's health research, gender analysis, and participatory action methodologies, and to ensure gender issues and analysis are part of funding criteria.
- Encourage innovative communication strategies by setting a target of communicating women's health research findings to 100% of the affected group and building outreach strategies into the project.
- Women's health researchers and agencies should educate governments, finance ministers in particular, of the links between their policies and women's health.
- The Women's Health Bureau should fund an independent review of the Bureau's work toward implementing the National Symposium recommendations and make the report available to the public.

## INTRODUCTION

For decades, feminist researchers have shown how societal values affect every aspect of research, from the choice of research question to methodology to the dissemination of the results. A society in which women are overlooked and do not have an equal voice produces research in which women are overlooked and whose concerns are not reflected in research (see Benston 1982; Birke 1986; Bleier 1987; Fee 1986; Harding 1986; Hubbard 1989; Imber and Tuana 1988; Keller 1985; Levin 1988; Longino 1989; Namenwirth 1986; Potter 1989; Rosser 1984; Sayers 1987).

Gender inequities obviously still exist in health research. For example, heart disease research is still focused on men although it is also the leading cause of death among women, and is often misdiagnosed in women because women manifest symptoms differently from men.

Lefebvre (1996) and Cohen and Sinding (1996) outlined in detail the development of women's health research in Canada and the slow but sure changes to mainstream health research and funding agencies. Instead of repeating their studies, this paper examines the components of women's health research: research relationships, research questions, ethics, methodology, dissemination of results, policy and action links, and offers recent "best cases" of most of these in Appendix A. In addition, the paper touches on current challenges, such as bringing what we know about women's health research to the emerging Canadian Institutes of Health Research.

## THE RESEARCHERS' RELATIONSHIP TO THE RESEARCHED

There are challenges of power and perspective even within participatory action women's health research performed by women on health determinants and policy questions:

Research relationships often reflect the kinds of relationships we have in society, and issues of power and control will differ from one setting to another. For example, most research involves researchers who are in more powerful positions than those they are researching (Muzychka et al. 1996).

In feminist health research, those performing the research may not share the perspective of those being researched, and may not reflect the diversity and concerns of the research participants. Some ways to reduce the impact of this are:

- perform community-based research, which is directed by the community from choosing research topics to design to dissemination of results
- engage in team research with team members who reflect the diversity of the research population
- establish research partnerships
- pilot the research with participants and use their feedback to make the research design more effective.

Research relationships can affect every aspect of health research from choosing research topics, to study design, to how to use the results.

## RESEARCH TOPICS

In her overview of women's health research in Canada, Lefebvre (1996) stated that "...the biological determinants addressed most directly by health care today, i.e. the biomedical, do not reflect those determinants having the most profound effect on women's health and health care needs". The five Centres of Excellence for Women's Health have begun to correct this imbalance. However, gaps remain.

Women in the Nova Scotia Black community, for example, have no data on their health

concerns. Most research on race and health is American, but the context is mainly one of inner-city African Americans with no universal public health insurance. The US National Cancer Institute found that mortality due to breast cancer is declining among white American women, and increasing among African American women, who already suffer a much higher rate (Kosary, Ries and Miller 1995). Is that true of Canadian Black and Caucasian women? There could be environmental factors that are different, which might increase or decrease the risk for Nova Scotia Black women, such as the proximity of toxic waste dumps near their communities. What about Toronto Black women, who are not one genetic and cultural community but many – from Canadian-born to Caribbean, to Somali, to Namibian, and more. As well, the US National Cancer Institute speculated that lesbians are at higher risk of breast cancer (Plumb 1997). What about Black lesbians? Is their risk double, or the same? No one knows. Who will do Canadian research on Black lesbian health, and who will fund it?

Vuyiswa Keyi (1999) raises good questions about who conducts research on Black women's health and how accountable it is to Black women across Canada. She cites work on female genital mutilation (FGM) that claimed to be working with the community, when in fact the community was only used as a data source.

The Maritime Centre of Excellence for Women's Health has taken a positive step in its recent funding of a project on Black women's health, in which the project team is comprised of researchers, peer reviewers, and team leaders from the Black community of Nova Scotia. The Black Women's Health Project's mandate is "to promote holistic health in Black communities of the Halifax Regional Municipality, specifically as it relates to Black Women, with an emphasis on the determinants of health."

The project "will also provide a stepping stone for ongoing and further research into the health and health issues of Black communities throughout Canada."

Karen Blackford (1999) discussed how it tends to be women with disabilities who do research on women with disabilities. Multiple oppressions means there is a smaller pool of people with fewer if any resources to do research on their own populations. Because of societal and internalized homophobia, not all researchers who are lesbians feel free to be associated with lesbian health research.

This is a double-sided problem: Because of the lack of resources and other obstacles for women experiencing multiple oppressions, not much of this research is being performed by them, and neither are interacting variables such as race and sexual orientation considered in broad research studies. Bailey et al. (1999) state that "... relegating issues relevant to lesbians and gay men to 'special topics' renders our understanding of the human experience truncated". Getting an issue on the agenda is only the first step. Ensuring that it is dealt with in a way that is responsive to the community is the next step.

Breast cancer research is sometimes viewed as a model of success. There was a time when no one spoke of breast cancer – it was a taboo subject in the media, until breast cancer activists and the attention of an all-female House of Commons Sub-Committee on the Status of Women (now defunct) turned public focus on the issue in the early 1990s. The 1993 National Forum on Breast Cancer was the first time women living with breast cancer were invited to help shape public policy on this disease.

Although funding for breast cancer research did increase dramatically as a result, years later, all is not well. "The bulk of research money for breast cancer goes to studying mammography, to testing treatments and to genetic research

on mechanisms at the cellular level” (Batt 1998). For example, money for research on breast cancer prevention was spent on a Tamoxifen trial of 16,000 healthy North American women, which amounted to “disease substitution”, as Tamoxifen may help to prevent breast cancer, but its side effects include an increased risk of endometrial cancer and blood clots. “We wanted prevention to be a breast cancer priority, but drugging healthy women was not the strategy we had in mind” (Batt 1998).

Women still do not have control over what is studied, how, by whom and for what purpose.

## ETHICAL REVIEW

Vuyiswa Keyi (1999) says hoops that the research community expects women to jump through are a barrier to applying for research funding. Institutions that conduct ethical reviews have their own standards, which not all community research models may fit. Participatory action research may not even get past the review stage.

In a CRIAW ethics workshop, participants recognized that:

The actual use of, and compliance with, these [ethics] codes, particularly in university-based research, often focus on the legal protection of the researchers. This approach to thinking about research ethics is narrow and it does not reflect the changes we have seen in the practice of research, especially in a feminist context (Muzychka et al. 1996: 3).

The result was *Feminist Research Ethics: A Process* (Muzychka et al. 1996), a booklet of 189 questions research teams can ask themselves during the development and course of their research. This is discussed in Appendix C on gender analysis tools.

Unforeseen consequences may arise when researchers study marginalized groups to whom they do not belong. For example, in the nutritional health study of low-income women food bank users, breast-feeding women were screened out because of their different nutritional requirements and because supplementary programs were available to them. The researchers realized over the course of the study that the \$50 honorarium offered was an incentive for poor women to stop breast-feeding so they could qualify as a participant and receive the money. As a result, the researchers dropped breast-feeding as an exclusion criterion because they did not intend their study to encourage women to stop breast-feeding (Tarasuk and Hilditch 1998). Ethical questions involving women's lives and well-being may arise long after an ethical review has been performed. Flexibility and sensitivity to the study's effects on the participants are key to good women's health research.

## RESEARCH METHODOLOGIES

Participants in a health research study are called “subjects”. They are subjected to the research instruments and the outcomes observed. Researchers often feel they owe the participants at most, a copy of the research report when completed. Women's participatory action health research takes the opposite view: There is an advocacy component, which acts as a drawing card for the participation of marginalized groups. Some of the women suffering hunger and extreme poverty agreed to participate in a research project because the results would be used to advocate on their behalf (Tarasuk and Hilditch 1998).

## PARTICIPATORY ACTION RESEARCH

Action research is “gathering and analyzing information which is conducted for the purpose of social change, usually with a specific action as the goal. The action research process

itself may also contribute to social change” (Muzychka et al. 1996: 35). True participatory action research is a “model in which the control at all stages is rooted in the community/organization/women involved in the study, and not with the researchers” (Archibald and Crnkovich 1995).

There are significant barriers, especially for marginalized women, to obtain research funding, even to write proposals. “The specialized language of scholarship, which is the language of most research studies, adds another layer to the hierarchy of knowledge: first there is competence in English or French, then there is scholarly expertise” (Archibald and Crnkovich 1995). As such, communities must sometimes hire or partner with outside researchers in order to get their research needs met.

Appendix A includes case studies on Inuit midwifery research initiated by Inuit women; a study of female Toronto food bank users involving low-income women of various ethnic, racial and linguistic backgrounds as both interviewers and interviewees; and an evaluation of a program for people with disabilities designed and conducted by the participants in the program.

## **REFORMING MAINSTREAM BIOMEDICAL RESEARCH AND EXISTING HEALTH RESEARCH STRUCTURES**

As a reaction to the scientific and medical communities' insistence on double-blind research and its derogatory treatment of anything outside that model, some women's health researchers in turn believe that double-blind studies and other stalwarts of the scientific method are not as good as qualitative, participatory research (Sayers 1987).

Levin (1988) states that accepting the genderized origins of scientific knowledge does not mean that science itself must be rejected. In “A Call for Feminist Science”, Sue Rosser

(1984) encourages feminists to use methods and theories that will result in a richer and more complete science, adding to rather than abandoning traditional scientific methodologies. The goal is a holistic and realistic view of women's health, as Madeline Dion-Stout (1996) advocates about Aboriginal women's health, a “total environment” approach in which “...income and social status, social support networks, education, physical surroundings, biological and genetic makeup, child development and health services are key elements”.

Progressive women can make a difference in biomedical research. Harvard professor Dr. Camara Jones brings her perspective as an African American woman medical doctor into her research on methodologies, AIDS, and the relationship between racism and racial/socio-economic health differences. Closer to home, Dr. Lillian Dyck, the first Aboriginal woman to earn a PhD in biological psychiatry and the inventor of several patents, is a strong advocate for both women and Aboriginal peoples in science. She was honoured with a National Aboriginal Achievement Award in 1999 for her advocacy, and for bringing an Aboriginal perspective of connectedness with the environment in her research as an academic neuropsychiatrist, who does gender studies and specializes in stroke research (Wiens 1999; CBC 1999).

Some success has been achieved in mainstreaming women's health issues, in terms of recognition, funding and awareness of gender issues in methodology, as detailed by Lefebvre (1996) and Cohen and Sinding (1996). The latter describe the improvements as resulting from “struggles and alliances between health professionals, governments, women's groups, institutions, advocates, and industry”.

## THE CANADIAN INSTITUTES OF HEALTH RESEARCH

The 1999 federal budget established a process to create 10-15 Canadian Institutes of Health Research (CIHR), which will build on research bases in universities, health and research centres, teaching hospitals, federal and provincial governments, voluntary and private sectors by linking and supporting researchers. It will absorb the current operations of the Medical Research Council, and involve expanded funding for health research. It promises an integrated health research agenda across disciplines and regions. The guiding principles make no mention of gender equity or analysis (see Health Canada 1999).

A Working Group on the CIHR, Gender and Women's Health Research was formed, comprising over 20 academic and community-based researchers to work to ensure the integration of gender and women's health research in developing the CIHR. A list of members is included in Appendix B. The themes of the 10-15 institutes have not yet been recommended by the CIHR interim Governing Council. A participant at one of the information sessions of the CIHR travelling roadshow reported that a favoured idea seemed to be to create a "cutting edge" Institute of Child, Maternal and Women's Health. She said that she was disappointed at the "boobs and tubes approach" to women's health, and that this was indeed far from "cutting edge". The CIHR process is on the fast track: it will be in place by April 2000. Clearly the Working Group has its work cut out, and would perhaps benefit from Karen Blackford's (1999) advice to "network like crazy".

## RESEARCH ORGANIZATIONS

It would be interesting to know what percentage of health research is done or funded by the pharmaceutical, biomedical and biotechnologi-

cal industries; what sort of research is not being performed because of where other health research dollars come from (Medical Research Council, Social Sciences and Humanities Research Council, etc.), how projects are evaluated, and how sources of research funding affect research topics, methodologies and presentation.

The five Centres of Excellence for Women's Health are instrumental in focussing on the socioeconomic determinants of women's health, rather than the traditional biomedical approaches of the past (see Canadian Women's Health Network 1999). However, funding for these centres will run out in two years, and they must make their own sustainability arrangements. A Health Canada official says that she is sure that the centres will find alternative means of funding from somewhere. A researcher at one of the centres says, "The tap's going off as far as I know".

In the absence of the Centres of Excellence, who will perform and fund research on women's health, and how?

## DO WOMEN HEAR ABOUT THE RESULTS OF WOMEN'S HEALTH RESEARCH?

The Centre for Research in Women's Health and the Sunnybrook and Women's College Health Sciences Centre in Toronto hold research in progress seminars twice a month. The Women's Health Resource Centre in Toronto offers a selection of books, periodicals, CD ROM databases, etc. But what if you don't live in Toronto? The Women's College Hospital has a Women's Health Electronic Network Directory so those working in academic and community aspects of women's health can network. Magazines and periodicals such as *Women's Health Matters* and the Canadian Women's Health Network newsletter provide information to subscribers.

The mainstream media sometimes report the results of studies, but often only the controversial studies that contradict accepted theory, presented outside the context of the existing body of research. This can lead to confusion, for example about whether milk or wine is good or bad for you. These one-hit wonders in the press do not tend to emphasize things we know already about women's health.

If a woman is connected to the Internet or reads certain publications, she may hear about the latest trends in research. She may have the skills to inform herself about the gamut of contradictory research and evaluate its validity. If she is a low-income woman, a disproportionate number of whom are Aboriginal, visible minority, living with a disability or multiple disabilities, over 65, or under 25, her chances of having access to women's health research or the resources to implement the findings in her life are slim. As women tend to be the health-keepers of their families, low-income women's lesser access to health information has implications for low-income children and men as well.

The Canadian Research Institute for the Advancement of Women (CRIAOW) is attempting to establish an implementation strategy for each of its new research projects. For example, CRIAOW conducted a study on home care and women's vulnerability to poverty, and will put together a team to use the study to lobby governments and inform the mainstream health research and service provider communities, in addition to its usual process of sending word out to CRIAOW's own members – mainly feminist researchers and academic institutions. However, limited funding is a problem for NGOs like CRIAOW to widely disseminate its research. It has had to partner, for example, with *Chatelaine* magazine for its young women and body image research project. Not all projects lend themselves to mainstream partnerships, and good outreach ideas often exceed both funds and staff resources.

Please see Appendix A for a good news story about communicating research on Labrador Inuit women's health to Labrador Inuit women by a Labrador Inuit health agency.

## THE LINK BETWEEN WOMEN'S HEALTH RESEARCH AND POLICY

The BC Centre of Excellence for Women's Health undertakes policy analysis projects, all of which are related to the health research that was funded. For example, a study entitled "Senior Women's Utilization of Anti-depressant and Benzodiazepine Drugs" led to a policy impact and implementation study entitled, "A Community Advocacy Strategy for Policy Change: Action towards Better Policies for Benzodiazepine Prescribing".

But who is listening? Income is one of the primary determinants of health (National Forum on Health 1997). Health officials across the country may be aware of this, but their finance departments are not. Governments state their commitment to population health, while chopping social assistance and maintaining a large gap between rich and poor which have direct health impacts (UN 1998a). The majority of Canada's poor are women (Statistics Canada 1995). Policies that keep people poor or make them poorer have a disproportionate impact on women and their health. There is a gap between health determinants research and social and economic policies.

Policy agendas are decided in advance, before "consultations", despite the health implications for women. Some of those most affected by biotechnology – women of child-bearing age, all women with a disability, and racial and ethnic minorities – were not invited to the federal government's by-invitation consultation on formulating a national strategy on biotechnology. Some of the consultation participants who were invited felt that "ethical, social, and ecological concerns were pushed to the way-

side as the federal government stressed the need for Canada to become a 'world leader' in the development and use of biotechnology" (Hirschhorn 1998).

There is a gap between Health Canada's efforts and government commitments to women's health on one hand, and the socioeconomic policies of the federal and most provincial governments on the other. Women's health is more than women's health research. It is policy that enhances the health of women by addressing health determinants such as income and structural inequality.

## CONCLUSION

The interest in women's health research and incorporating gender issues into mainstream health research is there. Some tools exist, others are being developed. Many researchers are discovering participatory action methodologies. Networks are evolving, but major challenges remain:

**1. Health issues and priorities of lesbians, Aboriginal women, women with disabilities, low-income women, women members of ethnic, racial and linguistic minorities, young and senior women:**

Not only are these women often excluded from mainstream health research, but where research is performed on them (for example, osteoporosis research on older women) they participate only as subjects. Even in feminist research, there is often a gap in power and perspective between the researcher and the researched. Where these groups develop their own research projects, they often run into obstacles such as lack of resources, training and credibility among funding agencies. The Centres of Excellence and other agencies should do more to seek out and support members of these communities to engage in participatory

action health research. Funding agencies should encourage other researchers to engage in team research with team members who reflect the diversity of the research population; establish research partnerships with community organizations; perform community-based research, which is directed by the community from choosing research topics to design to dissemination of results; and pilot the research with participants and use their feedback.

**2. Adequate and accurate communication of women's health research findings to all women:**

Innovative strategies must be explored, perhaps getting health information out through social assistance cheques, child care centres, schools, radio programs, asking for a women's health segment on the local news to present research results in a practical and accessible way, columns in women's magazines, family health days at community health centres with nutritious food provided, etc. Modelled on successful efforts of gay men in preparing AIDS information aimed at gay/bisexual men, a similar strategy can be adopted for women's health promotion information: low-income women designing outreach for low-income women in an accessible way, off-reserve Aboriginal women coming together to hear about health findings of concern to them, and they themselves designing the outreach materials and strategies for other off-reserve Aboriginal women, etc.. Also of importance is to communicate women's health research findings to mainstream health researchers and service providers, and to educate these to incorporate gender considerations into their work. If women's health research is not disseminated, it might as well not be done.

3. **The consequences (or lack thereof) of women's health research for social and economic policies:** Although breast cancer activists and researchers have made an impact on health funding policy, there has been little visible impact of research on the determinants of women's health for income support and other policies. Part of every applicable women's health research project should include a dissemination strategy involving outreach to government, particularly finance ministers and senior officials, to show them how their policies are having an impact on women's health.
4. **The structuring of the CIHR so gender, diversity, and progressive methodologies are integral.** This is especially important considering the possibility that the CIHR or one of its institutes may replace all or some of the Centres of Excellence as a funding source for women's health research.
5. **Ensuring that policy recommendations of which governments are already aware are implemented,** such as the report of the National Symposium Women in Partnership: Working Towards Inclusive, Gender-sensitive Health Policies.

## **APPENDIX A: GOOD NEWS CASE STUDIES IN WOMEN'S PARTICIPATORY HEALTH RESEARCH DESIGN**

*Research initiated by the community, with positive consequences in the community*

The membership of Pauktuutit, the Inuit Women's Association of Canada, initiated a research project to document traditional midwifery practices. The interviews with Inuit women elders were conducted by an Inuk woman in Inuktitut. Participants commented that they were thrilled that an Inuk researcher was involved, and were open with her.

Before the federal government decided that Inuit women should give birth isolated from their families in southern hospitals, many Inuit women were experienced in midwifery techniques and whole families helped in the birth, bonding with the newborn immediately. An Inuit midwife had a special, lifelong, close spiritual relationship with the children she helped to birth, similar to the role of a godmother. Midwifery was not simply a skill, but part of the cultural and spiritual fabric of the community. The research itself sparked renewed interest in midwifery in communities, validated and respected the knowledge of elders which had been dismissed by white health professionals, and resulted in a Pauktuutit policy resolution on traditional Inuit midwifery (Pauktuutit 1995). This research was initiated, owned and acted upon by Inuit women. In order to receive funding for it, however, they had to find two southern academics who would put their names on the funding proposal.

*Affected Groups Involved in the Research*

The following is an example of academic/community/participant population collaboration in women's health research. In a survey of the nutritional intake and health status of 153 Toronto women food bank users, the University of Toronto Faculty of Medicine researchers collaborated with the Daily Bread Food Bank in a study that used feminist research methods and design. The researchers were concerned that the "...application of standard survey techniques to assess household food insecurity and related issues, the research interview could become yet another instrument of disempowerment for those persuaded to participate" (Tarasuk and Hilditch 1998).

In particular, the researchers felt that conventional survey techniques, "a hierarchical process in which the interviewer asks a series of preset questions...carefully scripted as to be standardized across interviews and to reflect value-neutrality" was inappropriate for women on social assistance who have experienced structurally similar interviews with officials to determine (in)eligibility for social assistance, food assistance, subsidized housing and other programs. Many of the standard demographic variables that the study needed to collect were the same as in these stigmatizing, humiliating eligibility interviews (Tarasuk and Hilditch 1998). In order to redefine research relationships, the researchers:

- Hired interviewers with an affinity to the participants. That is, the interviewers recruited were all mothers, had firsthand experience with poverty and food insecurity, had an interest in cooking, strong interpersonal skills, displayed personal warmth, an ability to work independently, paid attention to detail, and expressed empathetic, non-judgmental attitudes toward food bank users. These individuals had no prior research experience. They spent four weeks in training, and two weeks pilot testing the instruments and procedures.

- The insights of these interviewers during the training period, and those of the target population during pilot testing, were used to revise the study instruments. As a result, participants stated that the interview questions were “right on the nose”, and relevant to their lives.
- Each woman was interviewed by the person who recruited her and had interacted with her - in other words, was not passed on down the line to someone else as in bureaucracies she experienced.
- The participants were assured that they would not have to answer any question if they did not want to. As one of the confidentiality and anonymity measures, women were asked only for their first names, and these were not recorded on the data sheets. Participants later commented that this encouraged them to tell the interviewer everything.
- In the opposite of a double-blind study, interviewers explained to participants why certain questions were being asked and how the information would be used.
- Each participant was given a \$50 cash honorarium at the end of the study, to recognize the value of her time, and the fact that she was crucial to the study. Forty percent of participants said the honorarium was the primary reason for their participation, given their extreme poverty.
- Most participants were interviewed in their own homes, where they felt comfortable and in control, not in institutional settings.
- Participants without telephones or who did not show up to scheduled meetings were not dropped from the study but were accommodated. As a result, the researchers were successful in recruiting and retaining participants living in extreme poverty, experiencing violence, threats of eviction, mental and physical health problems, and transient living arrangements.
- Interviewers who witnessed domestic violence and crowded, poorly maintained living spaces identified and offered appropriate supports.
- The interviews were interactive, conversational and non-hierarchical. The interviewers shared information about themselves, and their own experiences as low-income mothers created a bond of trust with the participants.
- Filipino, West African and other immigrant women participants became comfortable when they discovered that the interviewers had experience with their foods and cultures.
- Women who weighed more than average felt comfortable describing their food intake to interviewers who were also large in size.
- Participants were not stopped from discussing issues outside the topic of the study. Enough time was allocated so that tangential conversations could take place, without sacrificing the collection of nutritional data and height/weight measurements.
- Some of the most “personal” questions were left to the third interview, based on the assumption that by then, trust would have developed.
- Interviewers actively offered support to participants, from sharing cooking tips and information about community services, to conducting mock job interviews to give participants’ confidence, to helping women stay out of abusive relationships.

- Exit interviews were conducted with participants to determine how they felt about the research. Participants felt it was a positive experience particularly because of the empathy and helpfulness of the interviewer. Several participants invited interviewers to maintain contact with them, and interviewers accepted. Genuine friendships were formed.

A Winnipeg evaluation of a program for people with disabilities who had never held a paying job went a step further. It had the participants themselves design the research from scratch, determining the questions and the measures of success. The training they received in research methodology and their success in designing a research study that passed a University of Manitoba ethical review, boosted their self-esteem, added to their skills, and fostered an interest in research (Blackford 1999).

#### *Women Communicating Women's Health Research Information*

Everyone now knows of the Boston Women's Health Collective and *Our Bodies, Ourselves*. Today, women living with various diseases and conditions have come together to form associations and provide information for other women. The Endometriosis Association (Ballweg et al. 1995) published *The Endometriosis Sourcebook*, a thick and useful guide to the latest research, treatment options, myths and physical and emotional coping strategies. The Osteoporosis Society provides a toll-free information line, and partners with business associations to produce fact sheets. One fact sheet on calcium intake, in partnership with the Canadian Pharmaceutical Association and SmithKline Beecham, is distributed through pharmacies across the country and reaches a wide range of women. But there are health determinants, such as exercise, that are harder to find well-off partners for because one doesn't have to buy anything (like milk or calcium supplements) to do it. One does not want to give the idea that exercise can only be bought from health clubs or from infomercials selling expensive equipment.

The Canadian Women's Health Network was formed after a consultation meeting in Winnipeg in 1993 with over 70 organizations involved in women's health. Participants included Aboriginal women, women of colour, immigrant women, women with disabilities, and lesbians. The potential is great to communicate information, network and share strategies across Canada about every aspect of women's health, including the best and most accessible ways of getting health information out to women.

There are local success stories. The Labrador Inuit Health Commission, an Inuit-directed agency conducts research locally among Labrador Inuit, and reports results back to the community in a series of easy-to-read fact sheets. One of these was on women's health, which also suggested and explained courses of action, such as what a Pap test is and why it is important (Labrador Inuit Health Commission 1999). Linda Archibald (1999) emphasizes radio and television call-in shows as important ways in which health research findings are communicated in Inuit communities.

#### *Women Taking Action on Health Research Information*

It is sometimes frustrating to work in women's health because we know more about women's health than most women and certainly than Finance Department policy-makers. We know all too well the link between income, oppression and health, and see little if any action on this. However, there have been some successes, and we are not always aware of the impact of our work. One of the most stark examples of how far we've come is the fact that until 1969, the dissemination of birth control information was illegal, but this is one excellent example of where women took control of an issue, changed government policy, and disseminated information to women far and wide.

There are less dramatic but important precedents. For example, Lorraine Greaves' book *Smoke Screen: Women's Smoking and Social Control*, which discusses the meaning of smoking to women, had a direct impact on changing the content of some smoking cessation programs to respond to women's perspectives. Whenever women's health research is incorporated into health information or services, women benefit directly from it. It is important not to think of research as being over when a report is published, but to make recommendations as to how the research can be used in practical terms and take a pro-active approach to getting it out to people who can make a difference with it.

#### *Women Working Together to Change Policy with Health Research Information*

The BC Centre of Excellence for Women's Health engaged in participatory action research on women's mental health that combined leadership, support and participation from women consumers of the mental health system as well as family members, mental health providers, women's health advocates and policy makers with influence in government. The impetus for this research was the BC government's release of a new mental health plan in 1998. Women involved in the BC Centre's Mental Health Reform Discussion Group (which meets monthly to discuss women and mental health issues and to develop research questions) were concerned that women's mental health needs might not be met in the implementation of the plan. They felt that further consultation with women in the mental health system was necessary. In response to this they collaboratively developed a research project that was designed to canvass a wide range mental health constituents about the needs and concerns of women.

From the outset, however, special attention was given to canvassing the views of women with extensive experience in the mental health system as consumer/survivors. Marina Morrow (Research Associate at the BC Centre and instructor in Women's Studies at UBC) and Monika Chappell (DisAbled Women's Network) were hired to carry out the research. The project was overseen by an advisory group of 15 members, eight of whom were consumers/survivors of the mental health system, including rural and urban Aboriginal women and lesbians, and representation from each of the funders, including persons whose role involved advising the BC Minister of Health. Consumers/survivors of the system were hired in each community to bring together two focus groups – one of women consumers and one that would involve service providers, policy makers and family members. In all 20 focus groups were conducted in eight BC communities. In addition, key informant interviews were conducted with 20 individuals with specialized knowledge of the mental health system. Care was taken to solicit women with diverse backgrounds (e.g., immigrant women, women of colour, Aboriginal women, women with physical disabilities and older women) and experiences but the focus was on women who had serious and persistent mental health problems.

In each of the focus groups time was set aside for discussion of networking and about building a politicized consumer/survivor movement. At least one focus group intended to continue to meet after the research was completed.

The research (which had not yet been formally released at the time of writing) appeared to be well-received both in the community and in decision-making circles as evidenced in feedback on several presentations. For example, the results of the project were presented at a conference sponsored by the BC Minister's Advisory Committee on Women's Health. This conference was organized in order to bring together policy makers, front-line workers in mental health and mental health consumers from some of the focus groups to discuss key issues arising from the report. The BC Minister of

Health and the Mental Health Advocate for BC also presented at this conference. An important factor in the acceptance of this project in the community was the leadership and involvement of consumers. A factor in the research receiving prominence, mainstream credibility and the ear of the Minister, at least at this initial stage, is the fact that influential people (including prominent consumer advocates) were involved at every step, as members of the Advisory Committee. The unique funding partnership between the BC Centre of Excellence for Women's Health, the BC Ministry of Health, the BC Ministry of Women's Equality and the BC Minister's Advisory Committee on Women's Health greatly facilitated this. Another factor was political will:

- The BC Mental Health Plan articulates a concern about the needs of diverse groups (women being one of those groups) and a commitment to consumer and family involvement in policy development;
- Since 1993, a gender lens is required for reviewing all provincial policies in BC.

This research demonstrates the role that alliances (i.e., between service providers, policy makers, academics and consumers) can play in designing research that has the ability to outline and discuss a variety of perspectives on mental health, while at the same time facilitate the leadership of women consumer survivors and a consumer-centred research design. This approach allowed recommendations to be developed based on the concrete experiences of women consumer/survivors in the mental health system.

## **APPENDIX B: MEMBERS OF THE WORKING GROUP ON THE CANADIAN INSTITUTES OF HEALTH RESEARCH, GENDER AND WOMEN'S HEALTH RESEARCH**

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## **APPENDIX C: GENDER ANALYSIS TOOLS FOR HEALTH RESEARCH**

*Feminist Research Ethics: A Process* (Muzychka et al. 1996) is comprised of a broad range of questions researchers can ask themselves throughout the research process, on topics such as goals and accountability of the research; including women of diverse abilities, ages, classes, cultures, ethnicities, families, incomes, languages, locations, races and sexualities in the research questions, methodologies and team; creating safety for women so women can speak about their realities; how to resolve conflict, share the work and credit within the research team; the effects of funding sources on the research; and much more.

The Centre for Research on Women's Health at the University of Toronto has posted a resource guide for health care professionals doing practice-based research on their web site at [www.utoronto.ca/crwn/pbrresrc.htm](http://www.utoronto.ca/crwn/pbrresrc.htm), which also includes a further list of web sites of organizations to contact. The World Health Organization and United Nations Development Programme now use gender-related indicators in health research (UN 1998b).

The Maritime Centre of Excellence for Women's Health is developing a gender equity lens project with the participation of Women's Centres Connect to develop a curriculum that would enhance awareness of gender as a determinant of health, and how to implement this knowledge as an underlying component of public policy.

Gender analysis tools must take diversity into account. They must include guidelines for researchers to look for and include information on all sorts of differences that are not immediately apparent. For example, women's health research on tobacco use should also take into account significant racial differences in metabolizing nicotine and the greater harm done to Black smokers than white smokers who smoke the same amount (Perez-Stable, Herrera, Jacob and Benowitz 1998).

Gender/equity analysis tools for health researchers should also include tips about possible group differences in perceptions and self-reports, for example, there are documented, albeit contradictory reports, of Black-white differences in self-perceptions of health (Larson et al. 1998; Coward et al. 1997). If a research study relies solely on self-reports of health status, possible cultural, income and gender differences in self-evaluation may come into play.

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