A Women's Health Research Institute in the Canadian Institutes of Health Research

A proposal submitted by
the Working Group on the CIHR,
Gender and Women's Health Research

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■ EXECUTIVE SUMMARY

Submitted by a working group of leading clinicians, researchers, health care providers, representatives of consumer groups, advocates and policy makers in women's health in Canada, this proposal recommends the establishment of a Women's Health Research Institute, as well as a systematic program for the integration of sex and gender across the Canadian Institutes of Health Research (CIHR). The proposal asserts that capacity is strong and growing steadily, and it spans the four research quadrants of the CIHR, as well as all of the regions of Canada. This capacity within the women's health research community is primed to make a significant, value-added, contribution to the CIHR. Conducting research that is interdisciplinary, committed to methodological diversity, and involves working collaboratively with diverse communities is already routine within the women's health research community. This comprehensive and integrated approach captures the qualities which the CIHR has identified as necessary to transform health research in Canada in the next century.

The inclusion of sex and gender as critical variables in all health research is central to this proposal. Experience has shown that research that includes these variables will improve health, save lives, and lead to savings in the health care system; their omission leads to poor science, weaker clinical practice, and less appropriate health care delivery. The working group proposes that the Governing Council of the CIHR assume responsibility for establishing and ensuring sustainability of a gender mainstreaming process within the CIHR. The Women's Health Research Institute will carry out the knowledge generation aspect of this work.

The women's health research community is currently involved in several projects to articulate a women's health research agenda which incorporates the four sectors outlined by the CIHR. Core themes in women's health research, based on priority setting fora over the past 10-15 years, are enumerated, and will be integrated into the Women's Health Research Institute's overall research plan.

Aside from research conducted under the auspices of the Women's Health Research Institute, inter-institute collaborations and shared initiatives (with co-levering of funds from a "strategic initiatives fund" in the Women's Health Research Institute) will be central to advancing women's health research within the CIHR. The Scientific Director will be, by necessity, someone who has the proven ability to work with a high level of flexibility and collaboration with a wide range of stakeholders. The Scientific Director will work with an Advisory Board consisting of individuals representing the research community and other key stakeholders in women's health. The proposal suggests a shared governance structure that reflects the notion of citizen engagement. Information diffusion will be a key activity of the Women's Health Research Institute. Existing avenues such as the Canadian Women's Health Network and the Canadian Health Network will aid in the diffusion of research findings and applications. This diffusion will extend to the critical arena of health policy.

The contribution to be made by a Women's Health Research Institute will help to improve the health and well-being of Canadian women and to build a high quality health care system in Canada.

■ INTRODUCTION

This proposal is submitted by a working group comprised of leading clinicians, researchers (biomedical, applied clinical and social science), health care providers, representatives of consumer groups, advocates, and policy makers in women's health in Canada (see Appendix A for a full list of members of the Working Group). Since the announcement of the Canadian Institutes of Health Research (CIHR), some members of the Working Group have been meeting to formulate a vision for a **Women's Health Research Institute**. Others associated with this process have been working to develop an agenda for women's health research within the emerging CIHR.

Following on premises elaborated in *CIHR 2000: Sex, Gender and Women's Health*[1], this proposal outlines the key contributions that a Women's Health Research Institute will bring to the larger structure of the CIHR. The women's health research community in Canada is strong and growing and, for many years, has been conducting the type of transformative and integrative research called for in the CIHR. We further argue in this proposal for a conscious, integrated main-streaming of sex and gender across all institutes of the CIHR, and call upon the Governing Council of the CIHR to establish evaluation mechanisms to measure the progress of this process across all institutes.

[1] Greaves, Lorraine, Olena Hankivsky, Carol Amaratunga, Penny Ballem, Donna Chow, Maria De Koninck, Karen Grant, Abby Lippman, Heather Maclean, Janet Maher, Karen Messing, and Bilkis Vissandjee. *CIHR 2000: Sex, Gender and Women's Health*. October 1999. This document can be found at http://www.sshrc.ca/english/programinfo/hidgpapers.html.

■ WOMEN'S HEALTH RESEARCH

> *Women's health research investigates how sex interacts with gender to create health conditions, situations and problems that are unique, more prevalent, more serious or have different risk factors or interventions for women. (Greaves et al., 1999, p. 3)*

Research in women's health constitutes an approach that is comprehensive and integrated, qualities that the CIHR has identified as necessary to transform health research in Canada in the next century. Frequently, women's health is mistakenly equated with maternal and reproductive health; these represent only a fraction of women's health concerns and areas for research. Women's health research further acknowledges the validity of women's life experiences and their own beliefs about what determines their health. Finally, women's health research aims to take into account diverse variables including race, ethnicity, age, socioeconomic status, geographical location, sexual orientation, and disability, addressing the particularly glaring absence of data on women of colour, immigrant women, older women, Aboriginal women, lesbians, and women with disabilities.

Women's health is an issue of fundamental importance to Canadians. Women account for 52 per cent of the Canadian population, and represent all age groups and sectors. For this reason, women cannot be viewed as merely another population health group for, indeed, they cut across and encompass all population health groups. Women are also affected by most diseases. Improvements and setbacks in women's health are felt not just by women but by families and communities since women are most likely to manage family health, and to perform most formal and informal caregiving.[2]

The Canadian government has made a commitment to gender equity and to women's health through a series of documents including: *The Canadian Charter of Rights and Freedoms* (1982), *Setting the Stage for the Next Century: The Federal Plan for Gender Equality* (1995), and *Canada Health Council: Building on the Legacy, National Forum on Health* (1997). On the international front, Canada has supported several key documents that proclaim the goal of improving the rights of women.[3] The Minister of Health, the Honourable Allan Rock, reinforced a commitment to women's health when he issued the *Women's Health Strategy* in March 1999. Several bodies and jurisdictions, including the Medical Research Council of Canada and the provincial governments of British Columbia, Ontario and Quebec, have also identified the need for distinct research on women's health.

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[2] In 1996, over 2.8 million Canadians, the majority of them women, provided home care/caregiving services to someone with a chronic illness or disability. In 1960, only 16 per cent of Canadian women over age 50 had a surviving parent; by 2010, this is expected to rise to 60 per cent (Maritime Centre of Excellence for Women's Health, 1998).

[3] Canada has contributed to and endorsed the following key international documents: *The Beijing Platform for Action, Report of the Fourth World Conference on Women*, Beijing, September 4,1995; *Program of Action, UN International Conference on Population and Development*, Cairo, September 5-13, 1994; *Women and Health: Mainstreaming the Gender Perspective into the Health Sector*, Expert Group Meeting Report, UNDAW, Tunis, September 28-October 2, 1998; and *United Nations Economic and Social Council, Commission on the Status of Women*, March 1-12, 1999. See also Rebecca J. Cook's *The Promotion and Protection of Women's Health Through International Human Rights Law*. Geneva: World Health Organization, 1994.

■ WHY A WOMEN'S HEALTH RESEARCH INSTITUTE

Women's health research studies how sex and gender interact and influence the experience of health, illness, disability, disease and the experience of seeking and receiving health care. Research clearly shows that sex is the most fundamental difference among human beings. Accordingly, what we learn about differences on the basis of sex and the social construction of it (i.e., gender) is instructive for all other sources of differentiation. Thus far, a great deal of research has taken for granted that humans are one (and male). A tremendous effort is now needed to fill in significant knowledge gaps so that we can better our understanding of human health.

One means of guaranteeing a climate of more comprehensive health research is by ensuring the inclusion of two key variables: *sex* (the biological differences between men and women) and *gender* (the different social and cultural experiences of women and men). Integrating sex and gender into health research is good science. It reflects the comprehensive vision of health identified by the World Health Organization and in this regard could be truly transformative within the CIHR. In order for research findings to produce positive results for health promotion and care, they must apply to all populations (see Table 1).

TABLE 1: GOOD SCIENCE AND WOMEN'S HEALTH RESEARCH

Good science...	Women's health research...
addresses identified gaps in knowledge or understanding.	identifies gaps in existing research through consultation with a range of stakeholders to form the basis of a research agenda.
ensures that research findings are generalizable.	recognizes that one cannot generalize to women what has been learned from researching men. Medical scientists have inherited a long tradition of doing precisely this, and are only slowly beginning to address and rectify this error. Sometimes the results of these errors are relatively benign, but they can also lead to improper diagnoses and damaging treatment. The quality of science suffers from this omission.
uses a mix of comprehensive and diverse methodologies to frame answers to complex research questions.	uses multiple methodologies, including qualitative, quantitative, interdisciplinary and cross-cultural approaches.
evolves from a commitment to studying health in its context.	involves paying attention to the interactions between gender and other determinants of health including income, race, education, sexual orientation, and environment.

Historically, most research has not considered these two variables, and has made assumptions about women's health based on research done on men. Hence, there is presently an uneven evidence base regarding women's health. In addition, we have inadequate information in relation to differences *between* groups of women with respect to race, age, ethnicity, ability, social class, education, etc.

The lack of appropriate sex and gender analysis has gone even further; it has contributed to poor science. For example, a long-standing history of excluding women from clinical trials has resulted in medications used on women on a "trial and error basis" once they are on the market. As well, research has overlooked some key determinants of women's health, such as the impact of violence. For years, violence went unnoticed in the health research community. We now know much more about this critical variable, but before we did, women were often blamed for their situation and prevention and treatment programs were non-existent. A lack of gender analysis has also contributed to our poor understanding of why women (especially during their childbearing years) are twice as likely as men to suffer from depression and anxiety.[4] In the area of occupational health, the exclusion of women from many studies on occupationally-related cancers has created the erroneous impression that women do not develop cancers as a result of workplace exposure.[5]

[4] Additional examples and the consequences of research which does not consider sex and gender can be found in Margrit Eichler's "Moving Toward Equality: Recognizing and Eliminating Gender Bias" (1999). See also Donna Stewart's "Depression, Anxiety and Gender" (1996) and "Women and Heart Disease" (1996) commissioned for the Canada-USA Women's Health Forum.

[5] More recent research suggests that women are indeed extremely sensitive to certain environmental carcinogens in the workplace, particularly when there are specific "windows" in development of organs, such as the breast. Chemical threshold levels are set based on the typical 180 lb. white male and may seriously overestimate the levels of exposure at which chemicals harm women's health (Messing, 1998).

■ ADVANCING SCIENCE THROUGH A WOMEN'S HEALTH RESEARCH INSTITUTE

A Women's Health Research Institute will ensure a contribution to good science through the following means:

☐ Research Questions That Include Sex and Gender

Research that includes sex and gender variables will improve health, save lives and lead to savings in the health care system; their omission leads to weaker clinical practice and less appropriate health care delivery. For example, cardiovascular research has largely focussed on male subjects even though heart disease is the leading cause of death in women. Consequently, it is often misdiagnosed in women because they may manifest symptoms differently from men. The interaction *between* sex and gender is also critical. In the area of mental health, for example, we need to better understand how socialization interacts with biology and neurotransmitters to produce different effects – increased depression in women, increased anti-social behaviour in men, more eating disorders in women, etc. Furthermore, research that includes sex and gender very often helps to illuminate the impact of (other) social inequalities in health.

☐ Research Processes Involving Collaborative Partnerships

Because women's health researchers recognize the physical, mental and social well-being of women (and not just that health is the absence of disease), their work often entails working with a broad range of partners, including users of services and women in diverse communities. This has been demonstrated by such centres as the Centres of Excellence for Research in Women's Health (located in Vancouver, Winnipeg, Toronto, Montreal, and Halifax), the Centre for Research in Women's Health (Toronto), and funding programs of the Conseil québecois de la recherche sociale and SSHRC (through the Community-University Research Alliances Program). For example, the Maritime Centre of Excellence for Women's Health is engaged in a project on black women's health that involves members of the black women's health community as peer reviewers, team leaders, principal investigators and researchers. In Toronto, University Health Network Women's Health Program has developed collaborative partnerships with multicultural women's groups, rural physicians, and international scholars to better women's health in diverse populations.

☐ Commitment to Interdisciplinarity

Women's health researchers recognise that it is impossible for any single discipline or speciality to have sufficient expertise to identify all of women's health risks and needs. By necessity and philosophical orientation, women's health researchers have long demonstrated a commitment to interdisciplinary work, and their interdisciplinary practices are a model to other researchers.

☐ Commitment to Methodological Diversity

A range of disciplines and philosophies, and a commitment to working with non-academic partners, characterizes women's health research. Inherent in this orientation is a commitment to

choosing methodologies that are best suited for a given research endeavour, drawing from a broad and comprehensive range. The transfer of knowledge about use of diverse methodologies (i.e., participatory action research) is also a key contribution that the Women's Health Research Institute would make to the CIHR.

These components of women's health research provide a "value-added" factor to the CIHR. With this foundation to build from, a rapidly growing network of women's health researchers, that integrate the four quadrants of research identified by the CIHR, has evolved across Canada over the past decade. This network has demonstrated an ability to work across and between disciplines while integrating the expertise of community-based organizations. A strong and growing network is in place to carry out the work of a Women's Health Research Institute within the CIHR.

■ INTEGRATING GENDER IN THE CIHR

Gender mainstreaming is a term used to describe the application of "sex and gender analyses to programs, policies, or research projects so that the effects on both men and women are identified" (Greaves et al., 1999, p.3). Assuming an ultimate goal of integrating sex and gender into all health research in Canada, it is incumbent upon the CIHR to ensure that both a policy and program of gender mainstreaming are established early in the creation of the governing structure in 2000.

Vivian Pinn, Director of the Office of Research on Women's Health at the National Institutes of Health, says that "accountability for and evaluation, monitoring and tracking of the activities of all the institutes regarding women's health should rest at the highest level in the organization. This is vital to the successful development and institutionalization of any substantive women's health research initiative." The view of the Working Group is that the responsibility for ensuring that there is a gender mainstreaming process, and that it is sustained, lies with the Governing Council of the CIHR. This is consistent with other federal initiatives. For example, in 1998 Canada sent representatives to the UN Expert Special Committee Meeting on Women and Health, where models for gender mainstreaming in the health sector were developed.

Within the CIHR, gender mainstreaming would entail two key functions: an *enabling* function designed to aid researchers in developing appropriate methodologies for the integration of sex and gender in all research, and a *monitoring* or accountability function designed to gauge how well research in the CIHR integrates sex and gender into the knowledge generation process. The two functions must remain separate, but both are necessary and neither is sufficient on its own.

The Women's Health Research Institute will be responsible for carrying out the enabling function. This would include institute-specific knowledge generation activities, and the provision of support to other institutes in order to facilitate the conduct of gender-sensitive research throughout the CIHR. Additional activities would include skill development workshops in the area of gender-based analysis, joint symposia, and collaborative projects with other institutes. The Governing Council will evaluate whether progress is being made in the integration of sex and gender across all institutes (the monitoring function). It is expected that the Governing Council will establish appropriate evaluative mechanisms to ensure that gender mainstreaming occurs within the CIHR.

Those involved in the Women's Health Research Institute have accumulated significant expertise regarding the integration of sex and gender into health research. They will work with other institutes in identifying gaps that exist (i.e., with an institute on cardiovascular health, knowledge gaps with respect to women and cardiovascular care would be a focal point) and carrying out research in collaborative partnerships.

■ WHAT WILL BE DONE: A RESEARCH AGENDA FOR THE WOMEN'S HEALTH RESEARCH INSTITUTE

☐ Context

Internationally, Canada is a leader in women's health research in areas such as perinatology, violence against women, breast cancer, occupational health and maternity care (see Appendix B for more on international women's health research being undertaken by Canadian researchers). Similarly, Canada has commitments with the United States regarding particular women's health research initiatives stemming from the 1996 Canada-USA Women's Health Forum. The Women's Health Research Institute will maximize these links, and provide an umbrella under which they can continue to flourish.

☐ Creating a Research Agenda

Yvonne Lefebvre, in her paper "Women's Health Research in Canada" (1996), states that while "a research agenda in women's health must be flexible to be responsive to arising health needs, the major health issues requiring research are readily identified." A Women's Health Research Institute will undertake a systematic integration of the various research paradigms, identify gaps, and set research priorities for women's health.

The women's health research community is currently involved in several projects to articulate a women's health research agenda, with a Women's Health Research Institute in mind. Funds from the MRC Opportunities program will help to develop the basic biomedical capacity. Funds from SSHRC and CHSRF have been used to develop the population health and social science approaches to women's health. An application for funding is currently under review by the Tri-Council to share and integrate the research agendas of biomedical, applied, and social scientists in women's health.

Canadian women's health issues, including topics for research, have been identified and grouped to date in the following Canadian surveys and fora (see Table 2):

TABLE 2: PRIORITY SETTING IN WOMEN'S HEALTH RESEARCH TO DATE

- "Issues and Priorities for Women's Health in Canada: A Key Informant Survey" of 53 experts on women's health, for Health and Welfare Canada's Health Promotion Directorate (1986).
- In 1990 an overview of women's health issues, "Working Together for Women's Health: A Framework for the Development of Policies and Programs," was prepared by the Federal/Provincial/Territorial Working Group on Women's Health.
- In 1994 the MRC Advisory Committee on Women's Health Research Issues conducted a survey of women's research areas grouped around the health issues outlined in the above document, with expanded biomedical categories.
- In 1994 the Canadian Advisory Council on the Status of Women held a national symposium "Working in Partnership: Working Towards Inclusive, Gender-Sensitive Health Policies."
- A strategic objective of the 1995 Fourth World Conference on Women (the Beijing *Platform for Action*), endorsed by Canada, was to "promote research and disseminate information on women's health research."
- At the 1996 Canada-USA Women's Health Forum, workshops were held and recommendations tabled on key women's health issues, environmental health impacts, occupational health impacts, health aspects of violence against women, reproductive and sexual health, and health issues relevant to Indigenous women. The following four areas for joint initiatives were identified: Breast Cancer, Information Clearinghouses and Networks, Research, including clinical trials, and Tobacco Use Prevention, focused on girls, adolescents and young women.
- The 1999 Health Canada's *Women's Health Strategy* also recognized the importance of the Beijing and Canada-USA recommendations, "the need for more research, particularly on the links between women's health and their social and economic circumstances." The strategy was "developed to (1) promote understanding of the distinct nature of women's health issues; and (2) address the biases and insensitivities of the health system to women and their issues."
- In 1998 the action plan "Improving the Health of Women in the Work Force" was developed by the Canadian Researchers and Representatives of Women Workers, March 26-28, 1998, Montreal, with the support of the Women's Health Bureau, Health Canada (http://www.unites.uqam.ca/cinbiose).

■ CORE THEMES

Table 3 synthesizes identified health issues outlined in the above documents with some examples of research agenda items. It is offered to demonstrate the Women's Health Research Institute's intent and ability to conduct research in the four CIHR quadrants. The issues are divided according to commonly accepted classifications of types of women's health research. The list should not be viewed as definitive, but as a work in progress.

TABLE 3: CORE THEMES IN WOMEN'S HEALTH RESEARCH

Health Issues Unique to Women
Mental Health: body image, sexuality, sexual expression; needs for gender-sensitive training of professionals.
Violence Against Women/Girls: sexual abuse, rape, wife abuse; costs to health system; harassment in the workplace; exploitation by professionals in the health system.
Pregnancy and Childbirth: teens**;** medicalization of pregnancy and childbirth; impact of genetic testing on pregnancy.
Unintended Pregnancy: safe, low-technology contraception; male involvement in contraception; long term effects of Depo-Provera; DES; IUDs; hormones; oral contraceptives; surgery (ligation, sterilization).
Older Women: improving treatment for stress incontinence; reducing the risk of fractures; cardiovascular disease; osteoporosis.
Reproductive Health: infertility causes and prevention; reproductive tract infections; PID; STDs; menopause; effects of HRT; PMS; pain and discomfort in the reproductive cycle; medicalization of reproductive health.
Female Cancers: breast, including environmental chemicals and risks; deaths from cervical cancer, i.e., social determinants in motivation, access to prevention, and higher rates of cervical cancer among Aboriginal women.
Health Issues More Prevalent in Women
Mental Health: depression; anxiety; senior women and depression; eating disorders and socialization; low self-esteem; gender differences in experiences and coping with stress; stress and the immune system; psychiatric hospitalization; suicide attempts; somatization; gender bias in diagnosis, defining pathology, and treatment; senile dementias.
Violence: child sexual abuse, rape; economic and psychological abuse of elderly women.
Poverty: social determinant of ill health; women and poverty; low income single parents (most are women); senior women and poverty.

Health Issues More Prevalent in Women Cont'd

Quality of Life: 68 per cent of women report tiredness as a major complaint; feeling under stress; disturbed sleep.

Active Living: women of all ages are less active; encouraging healthy behaviours that relate to values, lifestyles and roles.

Occupational Health: 80 per cent of health care sector workers are women; unpaid caregivers; risks in traditional women's work; workplace pressure; double workloads; work stress index is much higher for women; repetitive strain injuries; lengthy periods of inactivity (i.e., sitting position).

Autoimmune Disorders: arthritis, rheumatism; lupus.

Chronic and Degenerative Diseases: persistent fatigue; osteoporosis, risk factors, and loss of agility and balance result in a high number of fractures; disability and death; respiratory disorders; digestive disorders; migraines; allergies.

Marginalized Populations: higher rates of certain diseases and disorders; impact of discrimination/bias in the health system.

Nutrition: malnutrition and poverty; busy schedules/double workloads and inadequate diet; weight preoccupation and malnutrition.

Prescribing practices: therapeutic effectiveness evidence and gender-based prescription patterns; overprescribing and poly-pharmacy in older women.

First Nations Women: differences in urban, rural and remote settings; discrimination; poverty; respiratory diseases; eye problems; ear problems; diabetes; hypertension; violence; childbirth practices in remote areas; effects of transfer of health services to local jurisdictions.

Adolescent/Young Women: stress; low self-esteem; reproductive health (including STDs and unintended pregnancies); alcohol, drugs, tobacco; nutrition (including eating disorders); fitness.

Senior Women: inappropriate and excessive use and abuse of prescribed and over-the-counter drugs; loss of function; the effects of high incidence of poverty on senior women.

Health Issues Less Understood in Women (and Groups of Women)

Mental Health: substance use and addictions; over-use of, and addictions to, prescribed drugs; tobacco addiction; alcohol addiction; depression; anxiety.

Cardiovascular Disease: public education to address knowledge gaps; differences in symptoms, course, treatment; risk factors; cardiovascular disease and depression.

Cancers: lung cancer deaths increasing; increasing rates of smoking among adolescent girls; public education and gender differences; prevention, detection, and treatment.

HIV/AIDS: rates among women increasing; understanding high risk behaviour among women; pregnancy and mother to fetus transmission; inexpensive prevention and diagnosis, treatment.

Environmental Health: reactions to environmental contaminants; toxic chemicals and cancer.

Unintended Pregnancy: gender norms and barriers in negotiating safer sex.

Health Issues Less Understood in Women (and Groups of Women) Cont'd.

Clinical Pharmacology: under-representation of women in drug/treatment modality trials.

Women with Disabilities: health problems associated with disabilities; economic insecurity in sections of the population; access to facilities; societal attitudes toward disabilities (discrimination); low self-esteem; increased risk of violence.

Immigrant Women and Women of Colour: barriers to adequate health care including lack of information and services, particularly for new Canadians; discrimination; poverty; cultural insensitivity of health care workers.

Policy Research

Impact of health reform and hospital restructuring on health care utilization by women.

Impact of health reform on the female health workforce and workplace conditions.

Impact of sex and gender in health services delivery and utilization.

Changes in delivery systems and impact on women's access to care.

Impact of sex and gender on type and intensity of medical intervention.

Role of consumers/lay persons and government in affecting policy change:
i.e., the key role played in the area of child-birth resulting in considerable change in practice (reduced interventions, introduction of midwifery, etc.).

■ EXISTING CAPACITY WITHIN THE WOMEN'S HEALTH RESEARCH COMMUNITY

Within the research community, a critical distinction can be made between *those who identify themselves as women's health researchers* and *health researchers conducting research on various diseases or conditions particular to women*. Women's health researchers take as their foundation a view of women's health that encompasses a broad, holistic perspective, incorporating a full range of health determinants (biology, age, race, income, ability, education, etc.). This perspective influences the research topics they choose, the methodologies they employ, and their selection of research partners. Health researchers conducting research on various diseases or conditions particular to women (i.e., innovative treatments for cervical cancer) may not immediately identify as women's health researchers. However, the Women's Health Research Institute will nurture both streams of researchers to improve the knowledge base about women's health. It will also offer the necessary support and resources for those interested in learning how to apply a broad, holistic approach to their existing research interests, thereby improving the health of Canadian women.

Attempts have been made to quantify the human capacity available in women's health research in Canada (see Greaves et al., 1999, p. 11-12). If we consider simply those who are directly affiliated with and/or employed by the existing women's health research centres across Canada, we arrive at a relatively crude estimate of 500 individuals. If we add to that list a broader range of stakeholders and those working in health research who are conducting research on or about diseases or conditions particular to women, the total is more likely in the thousands. The identification of the actual capacity will be refined over time, under the auspices of the Women's Health Research Institute.

Human capacity in women's health research in Canada is strong and growing steadily, and it spans the four research quadrants of the CIHR, as well as all regions of Canada. Existing women's health research centres offer important models for the CIHR to consider in creating the Women's Health Research Institute. The Centre for Research in Women's Health (CRWH) in Toronto, for example, has a base budget of nearly $2 million per year and is a WHO/PAHO Collaborating Centre in Women's Health.[6] In four years, University Health Network Women's Health Program in Toronto has obtained over $10 million in research funding. As well as creating the first Chair in Women's Health, several Women's Health Research Fellowships have been funded to train young researchers from Canada and abroad.

The Centres of Excellence for Women's Health Program, established by Health Canada in 1996, offer a model of collaborative research for the Women's Health Research Institute. To date, researchers in the Program have produced relevant results for women's health, particularly in the areas of health systems and services, social and cultural dimensions of health, and the

[6] The CRWH's breast cancer research program illustrates the Centre's multi-sectoral approach to research. The program presently includes research on perceptions of risk among women in high, medium and low risk categories, mastectomy versus lumpectomy in hereditary breast cancer, a physician survey to assess willingness to participate in Hormone Replacement Therapy, randomized control trials after a diagnosis of breast cancer, a study of long-term survivors of breast cancer and their physical and functional well-being, and detection of circulating tumour cells in blood of breast cancer patients.

health of populations. The Program has been successful in forming collaborative partnerships with community and other non-academic organizations as well as with federal policy makers. Funding for the program, which has amounted to $12 million over six years, will end in 2002. It would be prudent to capitalize upon this existing infrastructure and its large pool of women's health researchers, particularly in the social sciences and applied health sciences.

The Society of Obstetricians and Gynaecologists of Canada (SOGC) has partnered with the Working Group in its support of the proposed women's health agenda which identifies pregnancy, unintended pregnancy, and other aspects of reproductive health as health issues unique to women. A Women's Health Research Institute that is inclusive of the research mandate of the SOGC will ensure there are no gaps between our two initiatives and provide infrastructure and funding to support research which otherwise will not be a significant focus of other institutes. It will also provide support for development of stronger interdisciplinary, integrated approaches to reproductive research issues including violence against women during pregnancy and women with diseases which complicate pregnancy, two examples of research areas which will strongly benefit from the methodological diversity and collaboration central to the vision of the Women's Health Research Institute.

Building capacity amongst researchers in women's health will also be a priority of the Women's Health Research Institute. Consideration will be given to a re-training/re-entry grant program to provide opportunities for women who have taken a leave from their health research careers (for childrearing or to pursue other interests) to re-enter this field. This award program could also be used by women and men in related fields who would like to develop expertise in women's health and gender-based analysis. In an effort to retain junior researchers once they have finished their schooling, mentorship programs will also be developed in the Women's Health Research Institute. Programs such as Mentornet[7] will be explored to help women graduate students link electronically with women practising in the sciences.

[7] A non-profit US program developed to help young female graduate students in the sciences and engineering link electronically with women practising in those fields, through a software program which pairs women who have like interests, educational goals and fields of study.

■ STRUCTURE AND RELATIONSHIPS WITHIN A WOMEN'S HEALTH RESEARCH INSTITUTE

The Women's Health Research Institute will have a primary role in developing a coherent, strategic research agenda for women's health and, in collaboration with other institutes, developing an agenda for the integration of sex and gender in mainstream health research. The virtual nature of the institutes in the CIHR creates an enhanced environment to build on the existing networks of investigators, practitioners, policy makers, community agencies and members of the public in this country who are committed to, or have a stake in, advancing the research agenda for women's health. The structure of the Women's Health Research Institute will cultivate and encourage the interactive processes and cross-sectoral approaches which have been evident in the existing women's health research activities in Canada, as well as address the need for initiatives which creatively build more capacity among researchers in this critical area of health research. Fundamental to the structure of the Institute will be a capacity for flexibility and innovation, for creative initiatives which will build on the vision articulated for the CIHR.

☐ Scientific Director

The Scientific Director will be selected by the Governing Council on the recommendation of the President and Chief Executive Officer. This individual will have a leadership responsibility for inspiring and promoting research excellence and innovation, for building understanding, mutual respect and collaboration across disciplines and research sectors, and for the development of imaginative programs to attract and retain women's health researchers. Crucial to advancing the research agenda of the Women's Health Research Institute will be the ability of the Scientific Director to work in conjunction with other Scientific Directors on inter-institute initiatives, particularly to facilitate the integration of sex and gender into the research activities of other institutes. The Scientific Director will also play a key role in fostering new collaborative mechanisms (nationally and internationally) which will bring together researchers, voluntary health organizations, health professionals, industry, community groups, and policy makers to answer the research questions which will ultimately lead to the improved health of Canadian women and the improvement of our health system. In the start-up phase, it will be critical that the Scientific Director of the Women's Health Research Institute have key strengths in the areas of organizational development, the ability and the foresight to build on existing strengths and innovations, and to bring to fruition, within the first five years, outcomes from research activity which can be seen to be addressing key issues and gaps in the research agenda.

☐ Advisory Board

The Advisory Board will provide input to the Scientific Director in the areas of strategic planning, budget, policy, communications, ethics and other functions. The Advisory Board will represent or develop mechanisms to ensure that the views of the research community (inclusive of the four CIHR research quadrants – basic biomedical, applied clinical, health services and systems, and culture, society and the health of populations) are reflected in the activities of the Institute. In the Women's Health Research Institute, the research community will include established community-based researchers in this representation, thus ensuring that the richness of their

contribution to both setting the agenda and working to find solutions to complex health issues is captured in the CIHR. In addition, building on the innovative partnerships and the collaborative models already operating in women's health research in this country, efforts would also be made to ensure representation of other key stakeholders on the advisory committee, including advocates, policy makers, key volunteer organizations in the community, and users of the health care system. The notion of citizen engagement in both the development and operationalization of the women's health research agenda is critical to our ability to reach the overall goals articulated by the CIHR, that is, to improve the health and well-being of Canadian women, and to build a high quality health system.

In keeping with the CIHR vision to do research differently, we recommend that at least one-third of the membership of the Advisory Board be community/lay members, and that the Advisory Board have two co-chairs -- one representing the research community, and one representing the lay or citizen community.

Finally, along with the proposed standing committee structures proposed in the Institute Design Paper of the CIHR, the Advisory Board would constitute a specific standing committee to address priority areas for inter-institute collaborations and shared initiatives, particularly with the objective of facilitating the agenda of integration of sex and gender in the work of other institutes.

☐ Co-leverage and Co-support with other Institutes

Funding for a broad-based women's health research agenda has been more limited than for other research areas in Canada up to now. This has had an impact both on the extent of women's health research, and on the human capacity available to study health matters affecting women. The CIHR, particularly with its vision of interactive, collaborative, and cross-sectoral research, provides a very important opportunity to address the considerable gaps in knowledge and the critical need for the integration of sex and gender into all health research. Thus, in the first five years, through the articulation of its strategic plan, the Women's Health Research Institute would focus a significant amount of energy on capacity building through a large "strategic initiatives fund," using the CIHR toolbox of programs and through funding allocated through Institute Development monies. The focused activity will be addressing high priority areas where there are gaps in knowledge, and also developing capacity in the area of integration of sex and gender into mainstream health issues. This latter area of work will be accomplished through interactive and strategic partnerships with other institutes. The "strategic initiatives funds" are ideally structured to encourage co-levering of this nature, and these programs will not only generate important new knowledge, which will then be the subject of a growing number of investigator-initiated research proposals, but in addition, will greatly assist in capacity development. Current issues where there is a need are, for example, the area of cardiovascular health and cancer biology (i.e., lung cancer). The important role that these partnerships across institutes will play in the operationalizing of the women's health research agenda will be underscored by the resources committed by the Women's Health Research Institute to these activities.

☐ Information Diffusion

In keeping with models of existing women's health research centres in Canada and with the priority established by the larger women's health community, communication of research processes and findings will be critical. Through established links with the Canadian Women's Health Network[8] (a member of this Working Group), the Women's Health Research Institute will help convey the work of the CIHR to a larger public, and similarly, will bring information and recommendations from a larger public back to the CIHR. The Women's Health Research Institute, through the CIHR's Knowledge Exchange Office, will also work in concert with the Canadian Health Network towards electronic transmission of the work of the Women's Health Research Institute. The Women's Health Research Institute will additionally support such databases as the Cochrane Collaborative Database, the emerging Women's Health Surveillance Database of the LCDC, and the Breast Cancer Research Initiative.

Another means by which the Women's Health Research Institute will ensure its work has an impact is through policy research undertaken in consultation with key players in the policy arena. The women's health research community (as represented by the Working Group) has a solid record of collaborative policy-relevant work with. The Centres of Excellence for Women's Health, for example, have made policy relevance a high priority through collaborations between community and academic partnerships, drawing on the experience of the women's health movement which has effected policy change through lobbying around research findings. The Women's Health Research Institute will build on a solid record of producing research which makes an important contribution to the policy arena.

[8] The Canadian Women's Health Network is the designated women's health affiliate of the Canadian Health Network.

■ FINANCIAL CONSIDERATIONS

During the initial five years of the Women's Health Research Institute, we would anticipate a total annual budget of approximately $29 million. The allocation of these funds is outlined in Table 4.

TABLE 4: PROJECTED BUDGET FOR THE WOMEN'S HEALTH RESEARCH INSTITUTE

Activities	Annual Budget Allocation
▪ Investigator-initiated research funding for: ▪ individual grants ▪ research groups ▪ integrated teams	$10,000,000
▪ Strategic Initiatives Funding to be divided into two major categories of activities and support: ▪ Co-shared initiatives with other institutes particularly for gender mainstreaming research activities (up to $6,000,000), to include: ▪ research funding (individual, groups, teams) ▪ training awards ▪ career awards (postdoctoral and career research awards) ▪ career awards for health professionals; researchers eligible for re-entry or "retooling"; support for chairs ▪ Women's Health Research Institute initiatives to address articulated research agenda and identified high priority gaps in knowledge, and capacity development (up to $6,000,000), to include: ▪ research funding (individual, groups, teams) ▪ training awards ▪ career awards (postdoctoral and career research awards) ▪ career awards for health professionals; researchers eligible for re-entry or "retooling"; support for chairs ▪ international programs ▪ infrastructure support ▪ knowledge and technology transfer/policy linkage support initiatives	$12,000,000

Activities	Annual Budget Allocation
▪ Institute Development Funds for: ▪ Seed Funding for capacity building through consortia across other institutes to further develop the area of integration of sex and gender ▪ Development grants to address cross-sectional research questions where community capacity lacks development and resources (i.e., primary health care needs of immigrant and refugee communities) ▪ Mentored research in areas where there is existing but limited capacity	$5,000,000
Information Diffusion Activities	$2,000,000
Total Annual Allocation in Years 1-5	$29,000,000

APPENDIX A: MEMBERS OF THE WORKING GROUP ON THE CIHR, GENDER AND WOMEN'S HEALTH RESEARCH

Penny Ballem, M.D., Vice President, Women's & Family Health Programs, Children's & Women's Health Centre of British Columbia, Vancouver (Co-Chair)

Karen Grant, PhD, Associate Dean (Research), Faculty of Arts; Associate Professor, Department of Sociology, University of Manitoba; Chair, Executive Committee, National Network on Environments and Women's Health (Co-Chair)

Carol Amaratunga, PhD, Associate Professor (Research) and Exceutive Director, Maritime Centre of Excellence for Women's Health, Dalhousie University, Halifax

Pat Armstrong, PhD, York University, National National on Environments and Women's Health, Toronto

Robin Barnett, B.A., Chair, Board of Directors, Canadian Women's Health Network, Vancouver

Sharon Batt, M.A., Nancy's Chair in Women's Studies, Mount St. Vincent University, Halifax

Madeline Boscoe, Executive Coordinator, Canadian Women's Health Network, Winnipeg

Nadya Burton, PhD, Community Director, National Network on Environments and Women's Health, Toronto

Donna Chow, PhD, Associate Professor, Department of Immunology, Faculty of Medicine, University of Manitoba, Winnipeg; Board Member of the Women's Health Research Foundation of Canada Inc.

Anna Day, M.D., Consultant, Women's Health, Sunnybrook and Women's College Health Sciences Centre, Toronto

Maria De Koninck, PhD, Professor, Département de médecine sociale et préventive, Université Laval, Sainte-Foy, Québec

Linda DuBick, M.A., Director, Prairie Women's Health Centre of Excellence, Winnipeg

Gina Feldberg, PhD, Academic Director, National Network on Environments and Women's Health, Toronto

Anne Rochon Ford, B.A., Working Group on Women and Health Protection

Lorraine Greaves, PhD, Executive Director, BC Centre of Excellence for Women's Health, Vancouver

Olena Hankivsky, PhD, Research Associate, BC Centre of Excellence for Women's Health, Vancouver; Sessional Lecturer, Department of Political Science, University of British Columbia

Arminée Kazanjian, PhD, Associate Director, Centre for Health Services and Policy Research; Associate Professor, Faculty of Medicine, University of British Columbia, Vancouver

Yvonne Lefebvre, PhD, Vice-President of Research, University of Ottawa; Vice-President of Academic Research, Ottawa General Hospital; Professor, Department of Medicine and Department of Biochemistry, University of Ottawa

Abby Lippman, PhD, Professor, Department of Epidemiology and Biostatistics, McGill University, Montreal

Rhonda Love, PhD, Department of Public Health Sciences, University of Toronto

Heather Maclean, PhD, Director, Centre for Research in Women's Health, University of Toronto

Katherine Macnaughton-Osler, Community Co-director, Centre d'excellence pour la santé des femmes, Université de Montréal

Janet Maher, PhD, Community Relations Officer, Centre for Research in Women's Health, University of Toronto

Marika Morris, M.A., Research Coordinator, Canadian Research Institute for the Advancement of Women, Ottawa

Karen Messing, PhD, Director, Graduate Programme in Ergonomic Intervention; Professor, Department of Biological Sciences, Université du Québec à Montréal, Montréal

Linda Murphy, Manager, Research Programs, Canadian Health Services Research Foundation, Ottawa

Diane Ponée, MSW, Director, Women's Health Bureau, Health Canada, Ottawa (Health Canada liaison)

Lynne Dee Sproule, M.Ed., Manager, Centres of Excellence for Women's Health Program and Research, Women's Health Bureau, Health Canada, Ottawa (Health Canada liaison)

Donna Stewart, M.D., Chair in Women's Health, Toronto Hospital; Professor, Faculty of Medicine, University of Toronto

Bilkis Vissandjée, PhD, Associate Professor, School of Nursing, Université de Montréal; Academic Co-Director, Centre d'excellence pour la santé des femmes, Université de Montréal

APPENDIX B: CANADA'S ROLE IN INTERNATIONAL RESEARCH ON WOMEN'S HEALTH

A broad range of women's health research is being undertaken by several women's health research centres and programmes across Canada.

☐ The following is a sampling of sites undertaking international work:

Centre for Research in Women's Health (University of Toronto/Sunnybrook/Women's College)

Centre d'excellence pour la santé des femmes

CINBIOSE (Université du Québec à Montréal)

Eli Lilly Canada Fellow in Women's Mental Health, University of Toronto

Elizabeth May Chair in Women's Health and the Environment, Dalhousie University

Maritime Centre of Excellence for Women's Health

McMaster Research Centre for the Promotion of Women's Health

McMaster School of Nursing

National Network on Environments and Women's Health, York University

Prairie Region Health Promotion Research Centre

Society of Obstetricians and Gynaecologists of Canada (SOGC)

University Health Network, Women's Health Program, University of Toronto

☐ Examples of international research presently underway:

- Study of barriers and incentives to Pap smear screening with Ben Gurion University of the Negev in Israel (University Health Network)
- Aga Khan Projects in Pakistan related to the training of nurses and nurse practitioners (McMaster School of Nursing)
- Maternity Care in a Comparative Perspective (NNEWH)
- Training for Health Renewal: Canada and Mozambique (McMaster and Prairie Centres)
- Genetic mutations and hormonal-environmental risk factors for breast cancer in women in the Philippines and Pakistan (CRWH)

- Tem Breech Trial – involving 20 countries (CRWH)
- Retrospective review of "Baby Friendly" Hospital Programs – Russia (CRWH)
- Collaborative project on women's occupational health with Venezuela (CINBIOSE)
- International Federation of Gynecologists and Obstetricians Save the Mothers Uganda-Canada Project (SOGC)
- Social Autonomy, Economic Autonomy, Women's Health: Will this road lead to household welfare? (Centre d'excellence pour la santé des femmes, Maritime Centre of Excellence for Women's Health, Shastri Indo-Canadian Institute and the International Development Research Centre)

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