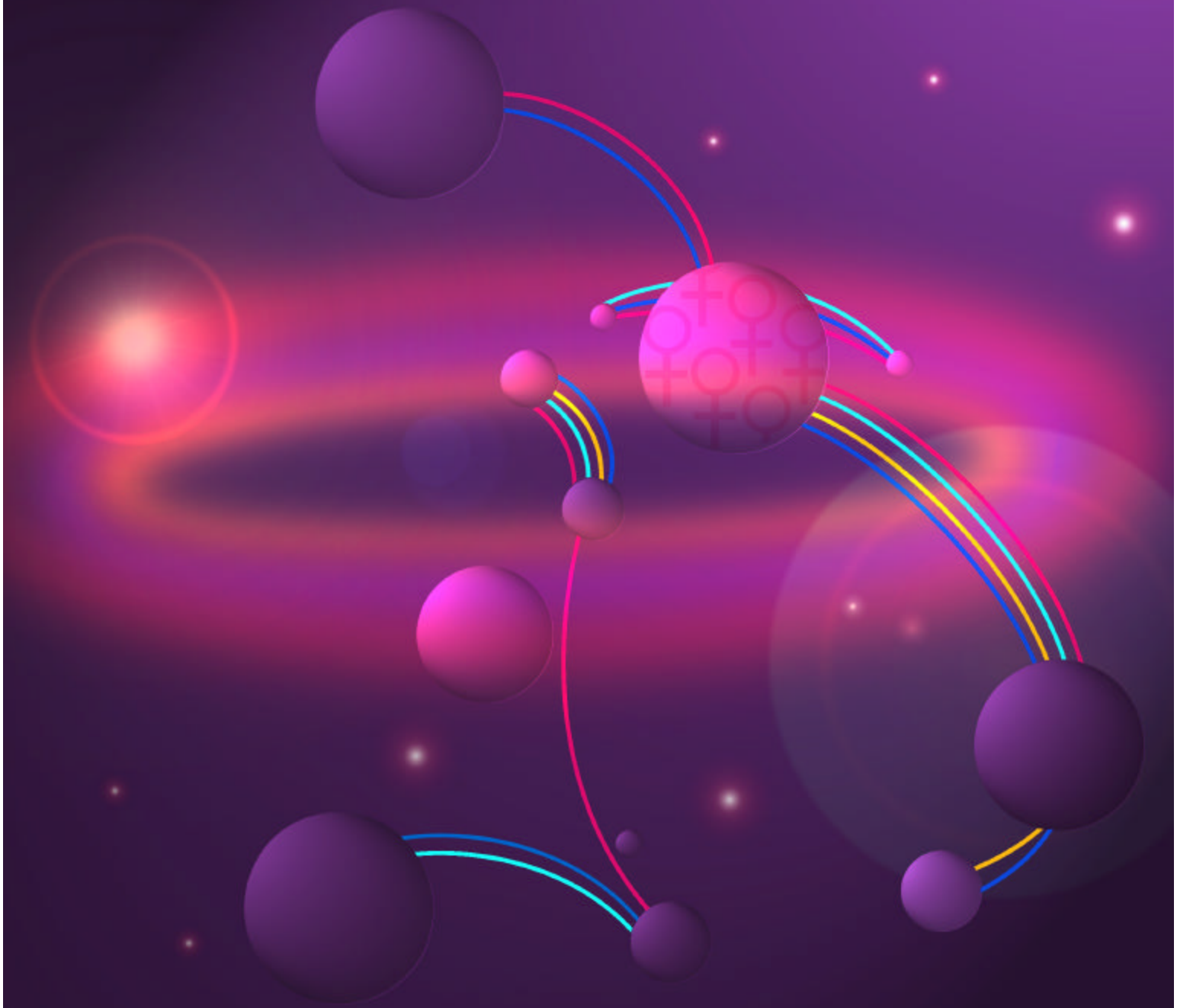
# CIHR 2000:

## Sex, Gender and Women's Health



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## Table of Contents

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Lorraine Greaves, PhD
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**"We are just beginning to understand and appreciate the difference between men and women in virtually every system of the body, as well as the way men and women experience disease." (National Institutes of Health – Agenda for Research on Women's Health for the 21st Century, 1999: 10).**

**"Pursuing integrated women's health research in the CIHR will thrust Canada into a leadership role in women's health." – Lesley Doyal, Professor of Health and Social Care, School of Policy Studies at the University of Bristol and author of *What Makes Women Sick?***

# ■ ABSTRACT

This paper investigates the issues of sex, gender and women's health in health research. The advent of the Canadian Institutes for Health Research (CIHR) planned for April, 2000 offers a tremendous opportunity for Canada to reorient its health research system to include sex, gender and women's health in a more systematic and effective manner. It will also foster the integration of basic biomedical, applied clinical, health systems and social and cultural dimensions of health research in a new research environment.

Both of these directions will contribute to the transformation of the substance and process of health research in Canada. Clearly addressing and including sex, gender and women's health in this plan from the outset will position Canadian health research in the forefront internationally. Most importantly, it will improve the quality of science in the health research field and decrease knowledge gaps related to the impact of sex and gender in human health and in particular, women's health.

This paper distinguishes between sex and gender as concepts and articulates the interactive relationships between sex and gender that affect health. Several examples are offered to illustrate this complex and dynamic relationship. Second, the field of women's health is examined and defined and the vast knowledge gaps in this area articulated. Several examples are detailed to illustrate the extent of what we do not yet know.

The rationale for extending and developing the field of women's health research is described. Women constitute 52 per cent of the Canadian population and cut across all age groups, life stages and population health groups. Women are affected by most disease categories and are affected by biomedical processes and research in as yet unknown ways. The impact of improving women's health is felt on women, families and communities as women form the vast majority of the managers of family health and perform most of the formal and informal caregiving in Canada.

Canada has been a leader in international fora to improve the human rights of women. In this vein, Canada has signed several documents to improve women's health and to establish mechanisms to ascertain the effects of sex and gender within its national machinery. Domestically, the Women's Health Strategy announced by the Health Minister, the Honourable Allan Rock, in March 1999 articulated Canada's recognition of the need in this field. Several bodies including the Medical Research Council of Canada have identified the need for distinct research on women.

The field of women's health research in Canada is strong and growing. Several Chairs and Centres of Excellence are devoted to women's health research and several hundred researchers identify as women's health researchers. This paper examines three operational options for developing women's health research further in the context of the CIHR. We conclude that a Women's Health Research Institute, with an integrated and educative gender mainstreaming component would accomplish the dual goals of addressing knowledge gaps in women's health research and including the important variables of sex and gender across Institutes of the CIHR. Finally, a conceptual model of a Women's Health Research Institute and a second model depicting the CIHR illustrates these conclusions.

**"A women's health research agenda which incorporates the four CIHR quadrants would be extremely far thinking in the field of women's health." – Martha Romans, Executive Director, Jacobs Institute of Women's Health, Washington DC.**

**"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." – Vivian Pinn, Director, Office of Research on Women's Health, National Institutes of Health, Bethesda, MD.**

# ■ I. INTRODUCTION

With the opportunity for transforming and integrating health research in Canada offered by the **Canadian Institutes for Health Research** (CIHR), an analysis of sex, gender and women's health and their relationship to health research is both timely and instructive. The inclusion of sex and gender as variables in health research is now recognised as good science, and the omission of these variables leads to problems of validity and generalizability, weaker clinical practice and less appropriate health care delivery. Further, such an omission will perpetuate the knowledge gaps with respect to women's health in particular. We reviewed a vast international literature on gender, sex, health, women's health, development and medicine. In addition, our team (See Appendix A) interviewed thirty-two key informants across four countries who are specialists in aspects of health research (See Appendix B).

### □ Why sex and gender?

**Sex** refers to the biological differences between men and women, while **gender** refers to the social and cultural differences experienced by women and men. In the determination of health status both sex and gender have profound impacts on Canadians. Sex can determine differential propensities for certain health conditions or diseases, different risk factors, or treatment requirements. Gender can determine different exposures to certain risks, different treatment seeking patterns, or differential impacts of social and economic determinants of health. All societies are divided along the "fault lines" of sex and gender (Papanek, 1984). In health, biological differences associated with femaleness and maleness create an immediate classification in treatment along sex lines. It is just as important to classify health research in its initial stages by sex-linked characteristics, in order to produce the highest quality of knowledge.

However, most critical for determining health in Canadian women and men is the **interaction** between the sex-linked factors and the gender-based factors that combine to affect health. For example, we are learning that sex-based factors affect the presentation of symptoms of myocardial infarctions. Gender-related factors affect the timing of treatment-seeking in women as well as the responses of health practitioners to women and men presenting with cardiac symptoms. Taken together, the combined effects of sex and gender affect health status, health systems responses, and eventual health outcomes.

Underlying this profound and important link is a serious need for more research on sex, gender and the interaction between the two. Clinical trials, basic laboratory research, epidemiological studies, surveys and ethnographic investigations have not always taken sex and gender into account. As a result, inappropriate generalizations have been made, assuming that research results apply equally to both males and females and/or are not affected by sex and gender. The lack of inclusion or misapplication of sex and gender as important and basic scientific concepts (across disciplines) renders research partial at best, and dangerously incomplete at worst. Indeed, it can result in continued suffering, illness or even death. The quality of science suffers from lack of inclusivity, comprehensiveness and limited generalizablity.

### □ Why women's health?

In research environments where sex and gender are poorly operationalized or ignored altogether, **women's health is particularly at risk.** As a result of decades of androcentric research we are collectively working with an uneven evidence base pertaining to women's health in particular. Additionally, we have little research information regarding differences between groups of women (race, ethnicity, age, ability, social class, etc). Fortunately, the speciality of women's health is positioned to be an integrated and transformative area of research, clinical practice, health promotion and health care delivery in that it includes data and information from all disciplines in determining paths to improving women's health. Critically, women's health research also utilizes a wide range of mixed methodologies (i.e. a combination of qualitative and quantitative methodologies) and sources of data in order to assess the complex interactions between sex and gender and health. Women's health has long recognised that it is impossible for any single discipline or type of specialist to have the requisite expertise to identify women's health risks and needs.

However, the clear development of a focus for women's health research within the evolving CIHR is needed to correct the unevenness of the evidence base, attract more researchers to the speciality and encourage a comprehensive set of variables to be included across the entire field of health research. Most importantly, it will provide better health outcomes for Canadian women and girls and their families.

# II. SEX, GENDER AND WOMEN'S HEALTH

"The use of an imprecise lexicon for describing differences between men and women in biomedical research has consequences for the conduct of science as well as for the clinical treatment of women" (Fishman et al., 1999: 19). There is little cross discipline understanding and usage of the terms sex and gender. Therefore their relationship to women's health research has been poorly operationalized.

## a)Sex

Sex refers to biological characteristics such as anatomy (e.g. body size and conformation) and physiology (e.g. hormonal activity or functioning of organs) (Adapted from Health Canada, Women's Health Strategy, 1999).

Sex is the basic biological variable indicating those characteristics that are distinctively male or distinctively female. Sex is a categorical variable that allows comparative investigations of these characteristics for potential identification of sex differences. Such information is critical to improving the reach of scientific research in health. Without seeking sex-linked data and disaggregating all data for potential sex differences it will remain difficult to generalize research findings and treatment options to both women and men with equal confidence and safety.

## b) Gender

Gender refers to the array of socially and culturally determined roles, personality traits, attitudes, behaviours, values, relative power, and influence that society ascribes to the two sexes on a differential basis (Adapted from Health Canada, Women's Health Strategy, 1999).

Gender is another important variable to include in all health research. Investigating gender is complicated due to the dynamic and changeable nature of the social and cultural systems in which we live. The forces of cultural norms and values determine gender. Such norms and values are both different from place to place as well as constantly evolving over time. As a consequence, our gendered experiences of health, illness, and health care are a complex blend of our maleness or femaleness mixed in with our cultural identity and social and generational locations. In short, gender is an evolving and relational variable, which often reflects power differences between groups of people.

For example, the cultural and socio-economic environments affect women's exposure to disease and injury, their diet, their access to and use of health services, and the manifestations and consequences of disease (World Bank, 1997). Attention to gender contributes to the understanding of differentials in risk factor as well as the manifestation, severity, frequency and social and cultural responses to disease. In addition, it can help us understand differences in access to resources that promote and protect health (information, education, technology and services), responses from the health sector, and the ability to exercise the right to health as a fundamental human right (WHO, 1998). Finally, attention to gender invariably highlights the many important interactions between gender and the other determinants of health, such as income, environment or education.

## c) The interaction of sex and gender

Sex and gender are two distinct concepts that interact to produce varied experiences of health and illness and impact on the design and delivery of health care. Further, our knowledge base about each of these is constantly evolving. While coronary heart disease and lung cancer were considered to be "men's diseases" as recently as 30 years ago, experience and research has shown those assumptions to be misdirected and incomplete. We now know that coronary heart disease and lung cancer not only affect both women and men, but affect women and men in different ways. Further, we have increased our knowledge base, through sex and gender based investigations in heart and cancer research about differences in symptomology, diagnosis, treatment and rehabilitation needs between women and men. In addition, by focussing on gender and its impact on behaviours associated with both heart disease and lung cancer (e.g. exercise, diet, stress, and smoking), we can increase knowledge surrounding best practices of prevention and intervention.

Sex difference research alone cannot be the cornerstone for women's health (Hamilton, 1996). Women's health requires an understanding of the implications for women of differences in the epidemiological profile between the sexes. This approach, which focuses on sex differences, highlights the specific health care needs of women and girls as a consequence of biology (and reproduction). However, biological and biomedical models do not explain adequately why population distributions of disease generally follow the contours of power, with the overall patterning closely associated with a society's economic and social structure, standard of living and degree of social inequalities (Krieger and Zierler, 1995). It is clear that the complex construct of gender interacting with biological, genetic or immunological sex differences create health conditions, situations, and problems that are different for women and men as individuals and as groups. In the words of key informant Lesley Doyal, this is an unequal "opportunity for health" between women and men.

Women's health status is affected by a host of social, cultural, political, and environmental determinants attributable to gender. Gender-based discrimination and inequalities are contributing factors in health disparities between women and men. They create disadvantage within health care systems and perpetuate ongoing inequality between the sexes in relation to access and utilization of services. For these reasons, the interaction of sex and gender as variables in health research is a crucial dimension in understanding women and men alike.

## d) 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.** Women's health research is an evolving but integrated speciality which utilizes and draws from basic biomedical, applied clinical, health services and systems and social, cultural and population health research areas. This comprehensive and holistic approach stems from an understanding of women's health as not the absence of illness, but rather the entirety of women's experiences of health.

The field of women's health is also responding to a large knowledge gap concerning both sex and gender influences on women's health status, health care, and outcomes. Patterns of health and illness in women and men show marked differences (WHO, 1998: 12). Certain diseases and conditions exclusively affect women, are more prevalent in women, or affect women differently than they do men.

In sum, women's health research is a field that is already philosophically integrative of all four areas of research articulated by the CIHR, and is potentially transformative in its reflection of the widely shared holistic understanding of women's health reflected by WHO. Secondly, women's health research can provide some models for addressing both sex and gender and their interaction as it affects women.

**"Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity. Women's health involves their emotional, social and physical well being and is determined by the social, political and economic context of their lives, as well as by biology."**
**(UN Platform for Action, 1995, par. 89).**

## e) Gender mainstreaming processes - how to integrate sex and gender?

**Applying sex and gender analyses to programs, policies, or research projects so that the effects on both men and women are identified is often referred to as gender mainstreaming (GM).**

Properly applied, GM illuminates the issues of sex, gender, and the interactive qualities between the two in health research and in the structures and processes that support the research endeavour. This is critical to ensuring improved science and improved health among Canadians. Various processes are used to accomplish the inclusion of sex and gender into activities such as research or policy development. In order to support successful gender mainstreaming, specific structures and initiatives are required in education, resources, support and training. Without a direct decision to implement the processes required to integrate sex and gender into health research in Canada, the processes of integration and transformation will be delayed. Further, the health of women in particular will be compromised. The vision presented in this paper includes this

very important integrative function and offers a model that will operationalize such a process throughout the CIHR in a productive and evolutionary manner.

## ■ III. BENEFITS OF INCLUDING SEX AND GENDER IN HEALTH RESEARCH

Women constitute more than half of the population of Canada. While women live longer[1] than men, they suffer greater burdens of morbidity, distress and disability (Doyal, 1998; Rahman et al., 1994). Women are more likely to suffer depression, stress overload (often due to efforts to balance work and family life), chronic conditions such as arthritis and osteoporosis, and injuries and death resulting from family violence (Toward A Healthy Future, 1999). Women present with more acute medical problems, are hospitalized at higher rates than men, use more prescriptive medications (International Women's Health Coalition, 1997), report feeling less healthy and have more restricted activity days (Toward a Healthy Future, 1999).

**"Women's health is devoted to the preservation of wellness and prevention of illness in women, and includes screening, diagnosis and management of conditions which are unique to women, are more common in women, are more serious in women [and] have manifestations, risk factors and interventions which are different in women." (U.S. Public Health Service 1991:149).**

### ☐ Better science and better research

Given that medical practice is informed by medical research and deals daily with life and death issues, it is of the highest importance that medical research be conducted in the most rigorous manner. Sex and gender blindness or bias constitutes a major flaw, which introduces a serious form of error into scientific research (Eichler et al., 1992: 62). Such omissions in research affect the reliability and integrity of science (LaFollette 1990: A56). They lead to serious problems with respect to external validity and generalizability. To omit or to inadequately represent women also implies incomplete and inadequate comprehension of human beings in general (Mura, 1989). There is international agreement that the recognition of sex and gender as key variables in research adds validity to overall findings (UN, 1996: 15).

### ☐ Research on women's health can improve and save lives

Because women have historically been excluded as subjects of research, much of the medical data informing prevention and intervention has been incomplete. Sex and gender insensitivity in research impairs the ability of clinicians to care for and to advise women patients (Wallis, 1994; Weisman & Cassard, 1994). It is clearly inappropriate if a health care system lacks services to prevent, detect and treat illnesses specific to women. The human costs and social implications of under-representation or exclusion of women from health research include death, disability, illness, suffering, reduced quality of life, and negative impacts on work, relationships and family. Improvements in health care depend upon empirically derived new knowledge that can be effectively imported into practice. Health research can lead to improved quality of life and enhanced health services, including more effective treatments, cures and improved access to health care for Canadian women and girls.

**"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."**

### ☐ Women's health research benefits families and communities.

Investments in women's health benefit women by improving their well being and quality of life. In addition, such investment and attention benefits families, communities and the broader society (SIDA, 1997: 1). To a large extent, the well being of children depends on the health of their mothers (World Bank, 1994: 5). International research supports the notion that direct attention to women's health research is not simply good for women - it also benefits men, families and communities (Jahan, 1995: 128).

### ☐ Research on women's health can lead to cost savings for the health care system.

According to Health Canada's study *The Economic Burden of Illness in Canada, 1993*, the cost of illness, disability and premature death in Canada for 1993 was $156.9 billion (Health Canada, Economic Burden, 1997: 8). This equates to 22 per cent of the Gross Domestic Product (GDP) or $5,450 per capita. Women account for 56 per cent of the direct costs of illness in Canada, reflecting higher disease prevalence and utilization costs (e.g. hospital care, physician billings and drug costs) (Health Canada, Economic Burden, 1997: 14). Of

particular importance is the fact that the report recommended the strengthening of research in order to minimize the burden of illness in Canada. The lack of information on the causes, severity, and distribution of women's health experiences, conditions and illnesses clearly lead to ineffective interventions and wasted resources (World Bank, 1994: 70).

**☐ Health research is good for the economy**

According to the Coalition for Biomedical and Health Research,[1] health research has proven to boost economic activity. It increases productivity in health industries and decreases the loss of productivity resulting from long-term disability (See Building on Canada's Brain Power: Improving Our Productivity Through Health Research. Brief submitted to The House of Commons Standing Committee on Finance, May 4, 1999). In addition, national economies, communities, and households - all of them highly dependent on women's paid and unpaid labour - benefit directly from investment in women's health (World Bank, 1994).

**☐ Women's health research is supported by the public**

According to a 1998 poll by Ekos, public support for new investments in health research is high. Eighty-six per cent of all Canadians felt that more money should be spent on health research in Canada. Two out of three people viewed health research as a source of pride. There is much evidence of different kinds of public support for women's health and women's health research. For example, a recent Angus Reid poll revealed that 33 per cent of all respondents and 68 per cent of all women wanted to see more coverage on women's health. The "Run for the Cure" initiated in 1992 by the Canadian Breast Cancer Foundation has wide corporate support (CIBC, Canadian Airlines, Ford Motor Company, Sobeys/IGA, Nike, Sheraton Hotels, Flare, CanPar, and The Running Room) and it attracts over 45,000 participants in 23 cities. The Centre for Research in Women's Health in Toronto is also a testament to the public support for women's health research. The Centre has raised over $11 million from the private sector including 25 corporations and philanthropic donors. Further, according to a province-wide consultation on women's health in British Columbia, health providers and consumers expressed serious concerns about the lack of funding being allocated to women's health needs (BC Women's Hospital and Health Centre Society, 1995).

**☐ Women's health research promotes social justice**

Because research can carry both burdens and benefits, equity requires that no one group receive disproportionate benefits or bear disproportionate burdens of research (Mastroianni, et al., 1994). Iris Marion Young (1990) argues that policy according special treatment to oppressed groups such as women promotes social justice. When the specific health interests of women, men, or other groups have not received a fair allocation of research attention or resources, a commitment to a just society requires actions. Sometimes, direct policies of preferential treatment toward these specified areas are required in order to remedy a past injustice and to avoid its perpetuation (Mastroianni et al., 1994: 5).

**☐ A commitment to women's health research will boost Canada's international profile**

According to our international key informants, the dual strategy suggested in this paper would elevate Canada to a leadership role in women's health research. Attending to both sex and gender within an integrated setting that includes the four crosscutting themes of the CIHR would be unique. Further, establishing a Women's Health Research Institute with the capacity to both do and facilitate research on the knowledge gaps in women's health would make Canada the leader in women's health research. In the year 2000, the Commission on the Status of Women at the United Nations General Assembly will be holding a Special Session to review implementation of the Beijing Platform for Action. At this point, Canada will have the opportunity to report on its innovative commitment to health research if the CIHR addresses and includes the issues of sex, gender and women's health in its structures.

**"If you ensure that the women's institute will interact with all others you've got a very different situation than if the others can say 'we don't have to worry about women because the women's institute is doing that.' " – Dorothy Broom, Senior Fellow, National Centre for Epidemiology and Population Health, Australian National Universitv. Canberra. Australia.**

# ■ IV. RATIONALE FOR WOMEN'S HEALTH RESEARCH

## a) Knowledge gaps in women's health

**Lack of a comprehensive approach to women's health**

Often women's health has been mistakenly equated with maternal and reproductive health. Maternal and reproductive health needs are only a fraction of women's health concerns and are often focussed in a time-limited life stage. The health needs of women as mothers are often reduced to the health needs of infants and children. This represents an obfuscation of women's health which can result in both a lack of clarity surrounding the health needs of women and children, as well as a deflection of attention from women's health in favour of child health.

This notion of women as "incubators" and/or primarily reproductive beings is entrenched in the "uterine tradition" (Matthews, 1987) of understanding biology, relations between the sexes, the practice of medicine and women's health. Not only is it demeaning and inequitable to place women second, it is also dangerous. If women's health needs are not seen as distinct from the foetus, infants and children, even during active reproductive years, it is possible to end up delivering less than adequate care to women. Linking the health needs of women and children inevitably equates the value of women with bearing and caring for children (Haseltine, 1997: 13) and is to be avoided in conceptualizing a progressive organization of health research, not to mention health services.

Taking sex into account, research must begin to see women's entire bodies as different from men's (Eckman, 1998: 130). It is now clear that there is a wide range of differences between men and women in size, weight, hormonal patterns, metabolism, biological susceptibility and resistance to a range of diseases and disorders that transcend reproductive systems (Doyal, 1998). However, both sex and gender must be recognized and fully integrated into the research process (Rosser, 1989; Cohen, 1991; Clarke, 1992; Messing et al., 1993). There is a different pattern in female morbidity and mortality at all ages related to a combination of genetic, biological, behavioural and environmental factors (Kane, 1991). In addition, congruent with the definition of women's health research noted earlier, there is a recognition that there are health areas requiring specific investigation for which there are no analogues in men (i.e. cervical cancer).

Finally, there have been failures to recognize that women do not constitute a homogeneous group. Women's diversity with respect to race, ethnicity, age, disability, socioeconomic class, education, geographic location and sexual orientation must be taken into account when questions regarding women's health are raised (Cohen, 1998: 89). Differences among women do not necessarily mean competing or divisive needs but rather indicate the differential impacts of their heterogeneous characteristics. These can be interpreted as intersecting inequalities (Chancer, 1997; Bush-Baskette, 1997) to which health research and health care systems need to develop culturally appropriate responses. The challenge is to establish a scientific knowledge base that will permit reliable diagnoses and diagnoses and effective prevention and treatment strategies for all women, including those of diverse cultural and ethnic origins, locations and economic status (Leigh & Lindquist, 1998: iii).

**"Our health issues become invisible because our needs are placed in conflict with the family. Women are not just in families." - Madelaine Boscoe, Executive Director, Canadian Women's Health Network.**

### □ Traditional research foci

Historically, women have not been adequately represented in research that produces empirically derived, new-found scientific knowledge that is incorporated into practice. While, women's health research in general receives insufficient funding, an additional problem is the disproportionately high amount of funding that is allocated to issues around women's reproductive capacities (National Forum on Health, 1997: 17). Consequently, there are critical data gaps for the diseases and conditions that women experience (Greenberger, 1999). In particular, there is a striking absence of research data on aboriginal women, women with disabilities, immigrant women, women of colour, older women, and lesbians (Canadian Advisory Council on the Status of Women, 1995). There is an enormous amount to do to improve knowledge regarding treatment of women with current illnesses, how to prevent the onset of new disorders and how to keep women healthy

(Mazure, 1999:1). As we approach the 21st century, there is much that we do not know about women's health, and increasing evidence that we do not yet know what we do not know in this realm.

### ☐ The biomedical paradigm

Much health related research is undertaken within the biomedical tradition where women have often been excluded as research subjects. The exclusion and under-representation of women in clinical trials and other important areas of health research has created critical data gaps for disease and conditions that women experience. There has been an assumption of no sex differences in some disease experiences and manifestations. Where the same diseases affect both women and men, many researchers have ignored possible differences between the sexes in diagnostic indicators, symptoms, prognosis, and the relative effectiveness of different treatments (American Medical Association, 1991; Kirchstein, 1991).

This ethical issue has been dealt with in the United States by passing legislation (NIH Revitalization Act of 1993) regarding the inclusion of women, children and minorities in clinical trials, and tying funding provided by the National Institutes of Health (NIH) to conformity with this legislation. Several key informants see this as an extremely important step in integrating sex into health research, and cite key research results that would not have otherwise been obtained. Detractors of this approach see it as expensive and perhaps counterproductive to launching clinical trials, and speculate that some new trials may not get done.

Even so, Canada lacks a comprehensive source of data and analysis on women's health (Canadian Advisory Council on the Status of Women, 1995). Data available on major illnesses are based on hospital separations (MRC, 1994). Indicators measured rarely reflect women's own perspectives on health and illness (Canadian Advisory Council on the Status of Women, 1995). Higher proportions of women than men are assigned diagnoses of non-specific symptoms and signs in both health service records and death certificates. Without adequate re-presentation of women in study populations, we cannot truly know whether we are most effectively diagnosing, treating and preventing illness in women (Kornblum, 1994: 122). No treatment or improper treatment can lead to worsening disease or even death (Ruiz & Verbrugge, 1997: 108).

### ☐ Social science research

Gaps in the biomedical are only part of the problem. Since many women's health problems are caused by or reflect societal conditions, women's health can often be most effectively promoted through changes in societal institutions and societal attitudes towards women (Matlin, 1998: 2). There is a need to understand more fully the social determinants of health. According to Canada's Women's Health Strategy, "more research, particularly on the links between women's health and their social and economic circumstances" is imperative. However, changes in social science research are also needed if the full range of influences on human health is to be understood. For example, women and men may conceptualize health differently such that standardized measures of health status and health practices will fail to capture the nuances of gender as a determinant of health. Social science health research and methodologies have not always attended to sex and gender. An example is the area of economic research and,

**...GAPS IN KNOWLEDGE ■ UNIQUE to Women or Subgroup of Women ie. Cervical cancer, Pelvic Inflammatory Disease, Menstrual disorders, Meno-pause, X-linked hereditary traits, Vulvar cancer, Vaginal cancer, Ovarian cancer, Toxic Shock Syndrome, Post partum depression, Vulvodynia, Endo-metriosis, Oral Contraceptives ■ MORE PREVALENT ie. Breast Cancer, Osteoporosis, Alzheimer's Disease, Violence against women, Multiple Sclerosis, Arthritis, Lupus, Scleroderma, Rheumatoid arthritis, Ankylosing spondylitis, Osteoarthritis, Thyroid Disease, Hypertension, Diabetes, Raynaud's disease, Urinary incontinence, Migraine headaches, Mental distress, Depression, Anxiety, Stress, Phobias, Generalized anxiety, Panic disorders, Anorexia, Bulimia, Gall Stones, Respiratory problems, Gastritis, Fibromyalgia, Intestinal cystitis ■ LESS UNDERSTOOD ie. Cardiovascular Disease (CVD): Myocardial infarction, Ischemic heart disease, Valvular heart disease, Peripheral vascular disease, Arrhythmias, High blood pressure, Stroke, Epilepsy, Biopolar disease and alcohol abuse, Gender**

in particular, economic costing in health. Many cost analyses have been undertaken without sex and gender specificity, and produce data on economic costs that are not disaggregated by sex or gender. Policy analyses and development derived from economic cost studies that do not take sex and gender into account can lead to faulty assumptions, costly mistakes and unintended consequences.

In short, both biological and psychosocial differences between the sexes affect etiology, risk factors, disease presentation, disease course, and response to preventative interventions or treatments (Weisman & Cassard, 1994). Both these dimensions are essential to women's health research.

## b) Women's interactions with the health care system

**Sex and gender-based differences lead to distinct needs and interactions vis-à-vis the health care system. For example:**

- **Women are the principal caregivers**

Women are the principal care providers in the family and the principal managers of family health. Women are often the primary caregivers to children, spouses, elderly and disabled relatives. They have the responsibility of recognizing ill health and seeking medical care when a health problem emerges. Recent health reform including deinstitutionalizaton has resulted in greater caregiving responsibilities for women without support of community services (Anderson, 1993). On average, a woman cares for her spouse for five years at the end of her husband's life and then goes on to live an average of eight years without the same type of intensive personal care (Mazure, 1999).

- **Women utilize the health care system more than men.**

In Canada, women have a longer life expectancy than men. However, they also spend a greater proportion of their lives in poorer health and therefore experience distinct life trajectories (Tudiver & Hall, 1996). Women are more likely to consult physicians, obtain preventative health care, consume drugs and have surgery. This utilization is often linked to problems connected with reproduction, violence against women, depression, and the effects of ageing (WHO, 1998). In addition, greater female longevity is associated with a greater lifetime risk of functional disability and chronic illnesses including cancer, cardiovascular disease, dementia and need for long term care.

- **Women are overly represented among the poor.**

According to Statistics Canada (Daily, 1998), women working full time throughout 1996, earned, on average, 73 cents for each dollar earned by their male counterparts. In Canada, 20 per cent of women live in poverty, and women make up 70 per cent of all people living in poverty (Grant-Cummings, 1998). Poverty is one of the strongest indicators of poor health (Doyal, 1995). As Susan Sherwin (1996: 198) notes: "the fact that people with low incomes are much less likely than others to have access to adequate nutrition, proper exercise, home and work environments free of toxins, and needed stress management programs surely falls into the category of justice in health care, but it is often overlooked in discussions of this topic."

**bias in disease classification, Lung cancer, AIDS, STDS, Tropical Diseases, Anasthesia, Pharmacokinetics, Pharmocodynamics, Sickle cell anemia, Schizophrenia, Dyslexia, Fetal alcohol syndrome, Psychological, Social, Cultural/Ethnic, Educational, Economic, Legal Determinants**

- **MORE SERIOUS ie. Smoking, Alcoholism, Skin Cancer, Environmental Contamination, Occupational and environmental health, Cardiovascular Disease**
- **RISK FACTORS ARE DIFFERENT Hypertension, Cardiovascular disease, Smoking, Tropical Diseases, Schizophrenia, Drug use…**

- **Women are the majority of health care workers.**

Women constitute the majority of workers in the formal and informal health care system (National Forum on Health, 1997: 5). The majority of nurses are women, many technical and support staff are women, and a growing number of physicians are women. Notwithstanding the "feminization" of health care, the location of power remains predominantly in the hands of men. Increasingly, as economic imperatives drive health care, managers control what services and health care personnel will be available to respond to the health care needs of the population. While women outnumber men as paid providers of care, the patterns of interaction

between women patients and health care providers are not fundamentally different from those in the past. This reflects the dominance of biomedical approaches which have historically been sex and gender blind.

## c) Canada's leadership in women's health

Canada is a signatory to a number of international conventions that explicitly affirm women's right to health as an integral component of human rights protection and promotion.[1] The right to the enjoyment of the highest attainable standard of physical and mental health is an integral part of the full realization of all human rights, and the human rights of women and the girl child are an inalienable, integral and indivisible part of universal human rights (UN Economic and Social Council, 1999. These conventions represent commitments on the part of their signatories to take concrete action to eliminate all forms of discrimination against women. Actions include positive steps aimed at respecting, protecting, and fulfilling women's right to health care.

**"It is a long term process to get health researchers to listen and be convinced that sex and gender differences are real." - Judith LaRosa, former Director of the Office of Research on Women's Health at the National Institutes of Health, Bethesda, Professor/Chair Community Health Sciences, Tulane University, New Orleans, LA.**

Internationally, Canada is considered a leader in women's health. We have numerous documents that broadly support equality, including sex and gender equality which are recognized as essential underlying principles of Canadian health policies and strategies. These include the *Canadian Charter of Rights and Freedoms 1982* (Section 15), *Ottawa Charter for Health Promotion*(1986), *Setting the Stage for the Next Century: The Federal Plan for Gender Equality* (1995). In this last document, the federal government states its commitment "to ensuring that all future legislation and policies, include, where appropriate, an analysis of the potential for different impacts on women and men" (17) (see also Appendix D).

More recently, women's health care and research needs have been explicitly identified as a major health challenge and priority in a number of studies/proceedings including *Health Canada Outlook 1996-1997 to 1998-99* (1996*)* and the National Forum on Health. According to the National Forum on Health, a broad population health strategy needs to focus on "providing increased support for gender and sex specific research." It determined that little is known about why the determinants of health appear to affect women and men differently and that there are not enough female researchers to promote women's health, nor enough women enrolled in clinical trials and other research initiatives to define risks and benefits of interventions, technologies and drug therapies (National Forum on Health, 1997: 19).

**"A CIHR Institute geared to child and family health could be restrictive, not open and capable of reflecting all the roles women play." – Judith Kazimirski, Past President of the Canadian Medical Association.**

Health Canada has embraced a population health approach that identifies twelve health determinants which shape the health status of Canadians. A commitment now exists to explore the various dimensions of women's health: the epidemiological, historical, psycho-social, cultural/ethnic, legal, political, and economic factors that impact on women's lives. In April 1999, Health Canada announced the Women's Health Strategy. This document identifies women's health as a priority and has developed a strategy to begin responding to women's health concerns. The Women's Health Strategy has four objectives:

1. To ensure that Health Canada policies and programs are **responsive to sex and gender** differences and to women's health needs.
2. To **increase knowledge** and understanding of women's health and women's health needs.
3. To support the **provision of effective health services** to women.
4. To **promote good health** through preventative measures and the reduction of risk factors that most imperil the health of women.

Recognizing the gaps, Canada's leading health research funding agencies have cited women's health as a priority. These include the SSHRC and the MRC. For example, in its Program Information under Section 5 – Inclusion in Research, SSHRC recognizes that "data for women are lacking and often must be inferred, despite

important differences which may render such inferences inaccurate and treatments or interventions based thereon more harmful. The inclusion of women in research is essential if men and women are equally to benefit from research. It advances both the commitment to justice and to rigorous scholarly or scientific analysis."

The MRC has also demonstrated its commitment to women's health. In 1994, the MRC Advisory Committee on Women's Health Research produced a report that acknowledged that "there are major differences in the health problems faced by women and men that should be recognized throughout the health research enterprise." Further, in his 1996 MRC President's Message on Women's Health, Dr. Henry Friesen underscored that "there is a growing concern about the level of attention paid to all health issues of special importance to women." He acknowledged that "pin-pointing women's health issues is no mean task. To begin, there are obvious biological and psychological differences between women and men, and these differences are an important area of future study...MRC places a high priority on the continuing study of health issues that concern women" (2).

**"...MRC places a high priority on the continuing study of health issues that concern women."**
**- Henry Friesen, President's Message, Medical Research Council, 1996.**

**"The inclusion of women in research is essential if men and women are equally to benefit from research."**
**- Social Science and Humanities Research Council, Program Information, 1999.**

## d) Women's health research capacity

In Canada, there is a solid foundation for a range of expertise in women's health research located across diverse sectors including the federal, provincial, public and private sectors, community, academia, women's groups and consumers (Tudiver & Hall, 1996: 27).

**There are over 500 self-identified, multi-disciplinary women's health researchers in Canada.[4]**

**There are 9 chairs in Women's Health.**

**Wyeth Ayerst and MRC-PMAC Health Program Clinical Research Chairs in Women's Health**
- Perinatology
- Reproductive Endocrinology
- Mental Health
- Cardiovascular Disease

**Toronto Hospital**
- Lillian Love Chair in Women's Health

**Toronto Centre for Research in Women's Health**
- Endowed Chair in Breast Cancer Research (University of Toronto and Sunnybrook and Women's College Health Sciences Centre). A second chair is currently being established UBC
- Endowed Atkinson Chair in Women's Health Research
- Shirley A. Brown Memorial Chair Women's Mental Health Research

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

**Lectureships in Women's Health:**
- May Cohen Lectureship in Women's Health (McMaster University)
- MacMillan Binch lectureship in Women's Health (The Centre for Research in Women's Health)
- Gail Regan Lectureship in Women's Health (The Centre for Research in Women's Health)

**Professorship**
- The Evelyn Bateman Professorship in Obstetrical Anaesthesia

**There are over 25 women's health, health-related centres, organizations, and government departments in Canada**

**Centres of Excellence for Women's Health**
- BC Centre of Excellence for Women's Health
- National Network on Environments and Women's Health
- Maritime Centre of Excellence for Women's Health
- Le Centre d'excellence pour la santé des femmes – Consortium Université de Montréal
- Prairie Women's Health Centre of Excellence

**Centre for Research in Women's Health (Toronto)**

**McMaster Research Centre for the Promotion of Women's Health**

**Alliance of Five Research Centres on Violence**
- BC/Yukon Feminist Research, Education, Development and Action
- RESOLVE – formerly the Manitoba Research Centre on Family Violence and Violence Against Women
- Centre for Research on Violence Against Women and Children (The University of Western Ontario's Chair in Violence Against Women and Children)
- Le Centre de Recherche Interdisciplinaire sur la Violence Familiale et la Violence Faite aux Femmes
- Muriel McQueen Fergusson Centre for Family Violence Research

**Hospitals**
- British Columbia Women's Hospital and Health Centre
- Sunnybrook and Women's College Health Sciences Centre
- IWK-Grace Hospital

**Other**
- Canadian Women's Health Network
- Clarke Institute of Psychiatry Women's Mental Health Research Program
- Federation of Medical Women of Canada
- Women's Health Bureau, Health Canada
- Women's Health Office, McMaster University
- Women's Health Research Foundation
- Women's Mental Health Program, University of Toronto
- World Health Organization Collaborating Centre in Women's Health
- Women's Health Bureau, Ministry of Health, BC
- Women's Health Research Foundation of Canada
- University of Northern British Columbia Research on Women and Health

### ☐ Areas of concern

While the capacity in women's health research is strong, there is a need to encourage more researchers to engage in such research (MRC, 1994). There is also a need to educate physicians about conditions affecting women's health and in developing competencies in women's health. There is no standard medical speciality in women's health. The same is true in other health professions. According to a NIH sponsored study of how women's health and gender-related issues are taught in the basic and clinical sciences in dental schools, no Canadian schools had an office or program responsible for co-ordinating and monitoring the integration of women's health and gender-related issues into curricula. None of the schools reported a mechanism to assist faculty in increasing their competence in women's health or in incorporating women's health and gender-related issues into their teaching (Silverton et al., 1999).

Finally, **there is concern about adequate funding for women's health research.** In a snapshot survey of three main Canadian granting agencies (NHRDP, MRC and SSHRC) of grants given in 1997-98, it is clear that both women-specific and gender-based research receive limited levels of funding (See Appendix C).

## ■ V. THREE OPTIONS FOR ADDRESSING SEX, GENDER AND WOMEN'S HEALTH IN CANADIAN RESEARCH

To meet the challenges presented by the issues of sex, gender and women's health three theoretical approaches and their respective operational manifestations were assessed using the results of a vast literature review and thirty key informant interviews with experts from four countries.

1. **Gender mainstreaming,** or the process of applying sex and gender analyses in all health research, with concomitant policies to support the inclusion of sex and gender as variables and lenses in all activities surrounding health research is the first option discussed. If this approach were operationalized, it would take the form of a Gender Mainstreaming Office in the CIHR Secretariat.

2. **A sex and gender specific approach to organizing women's health research** would focus attention on creating a research base and focal point for women's health research activity. The operational manifestation of this would take the form of a Women's Health Research Institute.

3. **A combined approach**, which would create a focus for women's health research but also encourage the integration of sex and gender issues into all other research institutes, would accomplish both development of new knowledge in women's health as well as inspiring more comprehensive analyses in other categories of research. The operational manifestation of this option would be a Women's Health Research Institute with an educative gender mainstreaming component.

### a) Option #1: Gender mainstreaming

Mainstreaming a gender perspective is the process of assessing the implications for women and men of any planned action, including legislation, policies and programmes in all areas and at all levels. It is a strategy for making women's as well as men's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that women and men benefit equally and inequality is not perpetuated (UN Economic and Social Council, 1998: L30. para. 4).

Gender mainstreaming (GM) first appeared as a strategy in the field of international development after the United Nations Third World Conference on Women (Nairobi 1985). Ten years later at the United Nations Fourth World Conference on Women in Beijing (Platform, 1995), the strategy of gender mainstreaming was explicitly endorsed in the Platform for Action adopted at the end of the Conference. The Platform states that "governments and other actors should promote an active and visible policy of mainstreaming a gender perspective in all policies and programmes, so that, before decisions are taken, an analysis is made of the effects on women and men, respectively" (para. 202).

While GM is a strategy explicitly to support the goal of gender equality (OECD, 1998: 12), it clearly emerged to correct the inequalities experienced by women. Technically, gender mainstreaming could and should illuminate the status of both women and men with respect to policies and programs. At the very least, GM should institutionalize the disaggregation of data concerning both females and males, and highlight differences experienced by both males and females. More specifically, GM would go further and unpack the experiences of both females and males and differentiate between them with a view to analysing the ramifications of living in sexed and gendered societies.

**Agenda-setting and integration**

The general objective of GM is to reorient the nature of the mainstream. Jahan (1995), a key authority on women and development argues that there are two basic approaches to mainstreaming - an "agenda-setting" and "integrationist" approach. The former attempts to transform the thrust of policy as it brings women's concerns into the mainstream, while the latter is concerned with how women's issues are integrated within existing activities (Razavi & Miller, 1995: ii). Clearly, these two goals are different and reflect the two required changes in health research as outlined in Sections II and III of this paper. Overall, the first goal is reflective of increasing the knowledge gap in women's health and applying such results to the health research agenda. The second goal is reflective of the anticipated results of integrating sex and gender appropriately into all health research in Canada. These two parallel goals would both be accomplished by a comprehensive and supported GM policy and program in the CIHR.

**Gender mainstreaming is not enough**

However, the experiences across the world with applying GM reveal that alone, it is not sufficient to accomplish its stated goals. First and foremost is the threat of homogenization and marginalization. This is the direct result of utilizing language and policy that is confusing. Focusing on gender may in fact avoid a focus on women and on funding women-specific issues (Neis, 1998). Further, if pursued as the only strategy for change, GM may actually divert resources to gender-based analyses that do not necessarily correct inequities. In short, a focus on gender, rather than women, is counter-productive in that it allows the discussion to shift from a focus on women, to women and men and finally, back to men (Baden & Goetz, 1997). If applied to health research, there is a real danger that in the process of restructuring and reorganizing, the evolving field of women's health will be remedicalised (reduced to illness and disease models) or at the very least homogenized into the mainstream (Eckman, 1998).

**Unintended consequences of gender mainstreaming**

Taken to an extreme, GM could deny women-specific disadvantages and the need for specific measures which might address these disadvantages (Kabeer, 1995: xii). Because true GM means introducing a gender perspective in a given policy field in order to make sure that the effects of policies are more gender neutral, it does not necessarily take the actual gender imbalances as the starting point for developing policies (OECD, 1998). The actual results of this in the women and development field have been that "in some instances 'gender' has been used to side-step a focus on 'women' and on the radical policy implications of overcoming their disprivilege" (Razavi & Miller, 1995: 41).

A final issue in measuring the effectiveness of GM reflects capacity. If women's health is totally "mainstreamed" before the mainstream has become sensitive and responsive to gender, that will be a loss for everyone (Broom, 1998: 42). The capacity to mainstream has been identified as integral to the success of implementation in developmental work (UNDP, 1999). This capacity includes analytic capacity, baseline understanding of socio-economic and gender issues, networking ability, negotiation skills, management of change skills, specialist thematic gender expertise, and knowledge of sources of gender expertise.

The operationalization of GM is typically in the form of a gender mainstreaming office. One example of this in health research is the U.S. Office of Research on Women's Health (ORWH). Established through legislation in 1993, this office is situated within the Office of the Director of the National Institutes of Heath (NIH). The ORWH promotes efforts to improve the health of women through biomedical and behavioral research. Its mandate involves strengthening, developing, and increasing research in women's health; identifying gaps in knowledge; establishing a women's health research agenda; ensuring that women are included as participants in NIH-supported research; and developing opportunities for women in biomedical careers. While its main objective is to integrate women's health into the NIH, several of our U.S. key informants perceive that the ORWH has been marginalized. The ORWH is seen as having a "policing" function which creates resistance and backlash from many NIH Institutes. While the ORWH does not carry out its own research program which is seen by some as a

limitation, it does set out a detailed research agenda for women's health (NIH, 1999). The ORWH expends its budget on research through co-levering and co-funding mechanisms with other Institutes in the NIH.

Drawing upon the U.S. experience, Jean Hamilton argues that "unless a separate pot of money is set aside for these issues, the research [women's health research] will remain underprioritized and underfunded" (Hamilton, 1992: 94). In addition, according to key informant Carol Weisman "even though they [ORWH] have developed a women's health agenda for the 21st century, they lack clout to follow through on it."

Twenty years after its introduction, there is growing consensus that GM can best be regarded as a process, and not a goal. There are no widely shared guidelines on how such a policy should be developed or implemented. Consequently, although many countries have accepted gender mainstreaming in principle, there has been no consensus built on how it should be conceptualized or operationalized (Rees, 1998: 190, 199; Mondesire, 1997: 6). It is fair to conclude that gender mainstreaming is still in its nascent stages and its many options, designs, and manifestations have yet to evolve (Group of Specialists on Mainstreaming, 1998). Its finest attributes are in capacity building and creating integrationist policies – the very qualities required for integration and transformation in the CIHR. It is not a comprehensive replacement, however, for clear agenda setting and research to fill the knowledge gaps related to sex and gender in women's health.

**☐ Operationalization - Gender Mainstreaming Office in the CIHR**

Gender Mainstreaming(GM) would involve a diffusion of responsibility for these issues across the range of departments and Institutes within the CIHR. The operationalization of GM would result in the identification of an office in the CIHR. This option would necessitate the systematic and explicit inclusion of sex and gender analyses in all CIHR research, structures, and processes. This would apply to all Insight and Challenge proposals across Institutes including the overall development of research agendas and methodologies. In addition it would be applied to the functions of peer review, knowledge exchange, and data analyses. It would also impact on the governance, resource allocation, reporting, and evaluation of CIHR Institutes.

**Pros:**

- systematic approach to improving the quality of science carried out by the CIHR;
- broader support for the CIHR and its results, more ready research uptake, knowledge transfer, and policy impact; and
- exposure of specific health problems that men face because of the social construction of male roles (WHO, 1998).

**Cons:**

- may be misinterpreted and resisted as a blunt and unnecessary monitoring function;
- may not be the most guaranteed or efficient route to building capacity support for the value-added impact of gender analyses ; and
- could focus on differences between genders, to the detriment of rectifying the knowledge gaps in women-specific health.

## b) Option #2: A sex and gender specific approach to organizing women's health research

Taking a specific approach to understanding the field of women's health is a strategy that has many parallels in other areas of policy and program, both inside and outside government machinery. Indeed, the conceptualization of Women's Studies as a discipline in universities has addressed the need for a focused location to bring together multi-, inter- and trans-disciplinary research and teaching on women. Similarly, a sex and gender specific approach to organizing women's health research has the potential to transform the field. First, such a locale would address the knowledge gap on diseases and conditions specific to women. Second, and of more permanent importance, such a locale would nurture the development of the theoretical framework and methodological approaches most suitable for addressing sex and gender in women's health.

Separate women's institutions such as women's colleges and women's hospitals have been created because of women's unique needs, vulnerabilities, or capacities, and sometimes to compensate for women's exclusion from mainstream institutions. Establishing separate women's institutions may also create effective competition with mainstream institutions that spurs them to adopt innovations that benefit women (Weisman, 1998: 193-195).

### ☐ Increasing Knowledge

Research exclusively on women can also move us beyond the important but underdeveloped understanding offered by comparative findings such as "men are more likely to..." or "women have more prevalence of...." Sex and gender specific analyses provide greater interpretative richness and give full voice to the complexity of the socially constructed meaning of sex and gender instead of simply trying to "control" for these (Kunkel & Atchley, 1996: 295). Given the importance of the interactions between sex and gender for women's health, it is crucial that a rich environment be developed in partnership with women and other stakeholders for cross disciplinary research using multiple methodologies to address women's health.

### ☐ Collaborative Partners

Finally, this approach would allow those who are specifically committed to women's health the autonomy to develop a research agenda to guide research programs, help shape funding priorities, and develop capacity in both young researchers and researchers across other fields. A sex and gender specific approach to women's health research would also respond to the high interest in health research among women in the general public. This would focus and empower women consumers to help develop research questions that are relevant as has been accomplished by the inclusion of lay people, such as breast cancer survivors, in peer review and other aspects of research. Community-academic partnerships carried out at the Centres of Excellence for Women's Health across Canada have focussed on including all sectors in designing research and disseminating knowledge. A focus on women's health research will encourage the creativity about scientific methods and approaches that is needed to conduct sensitive and sensible research reflective and inclusive of women's voices (Harding, 1986).

### ☐ Unintended Marginalization

Even so, there are possible problems with identifying a location and focus for women's health research. "Women-specific projects do little to challenge the marginal place assigned to women within development if the norms, practices and procedures which guide the development effort remain fundamentally unchanged" (Kabeer, 1995: 59). In addition, studying only women explains little about how gender relations are organized, and why they are so differently organized in different societies. Thus, patterns in women's or men's lives cannot accurately be described or explained apart from the oppositional relation between them (Harding, 1995: 298). This critique is crucial in supporting the notions of integrating and instituting sex and gender disaggregated data across all health research.

If addressing sex, gender and women's health is limited to a specific location, it will do little to change the systems propelling other fields. Nor will it obviously and immediately change the methods and theories utilized in other health research areas. A one-dimensional research institute on its own does not provide mechanisms for ensuring that overarching institutions change over time to minimize the gendered inequalities (and interpretations) that the policies may have been designed to correct in the first place (Weisman, 1998: 195). While this could be particularly damaging to a women's health research endeavour, the same would apply to the work of any research institute that depended upon transformations of approaches and attitudes to propel its work.

### ☐ Operationalization: Women's Health Research Institute

This option would focus and consolidate the critical mass of Canadian researchers across the four crosscutting themes and indeed, those associated with other Institutes, who are already investigating women's health issues. The Institute would foster investigations into the interaction of gender with biological, genetic, or immunological sex differences that create the health conditions, situations, and problems that are unique, more prevalent, more serious, or have different risk factors or interventions for women.

**Pros:**

- would integrate biomedical, applied clinical, health systems/services, social, cultural, and population health research;
- would focus on areas that have traditionally excluded women resulting in certain diseases, illnesses and conditions less understood, and
- would develop a research agenda to further the health of women and girls in Canada with special attention to specific health issues faced by diverse communities of women.

**Cons:**

- with no mechanisms for meaningful interaction with other Institutes, this option may lead to the isolation of women's health research, and
- without additional mechanisms, interest, and capacity, women's health research may not be developed in other Institutes.

### c) Option #3: An Enhanced Women's Health Research Institute

This option can best be understood as reflecting and rectifying the inadequacies of both a Women's Health Research Institute without a gender mainstreaming function and a gender mainstreaming office without a women focused research institute. A useful parallel is found in post-secondary educational institutions and in the experience of scholars in Women's Studies. Universities have most successfully included women in the general curriculum when they have both a focus on the study of women as well as outreach to other departments (Johnson & Hoffman, 1993).

**Both Gender Mainstreaming (GM) and specific research and policies reflecting sex and gender as variables can be seen as equally necessary and complementary strategies.** They are mutually supportive components of addressing women's health research needs. There is emerging evidence that both strategies are seen as integral to establishing a comprehensive strategy. Positive actions addressing concrete measures to address sex and gender need to be encouraged alongside a GM approach (Rees, 1998: 197).

Historically, discussions about GM and about sex and gender specific initiatives have often been dichotomized, and have manifested as two separate and distinct policy options. GM and (sex and gender) specific approaches are respectively process and content. The goals of both are overlapping but not the same. Lastly, comprehensive GM benefits both women and men directly, whereas a specific approach is often designed to correct and fill in knowledge gaps.

Hence the discussions about separation versus integration are often couched in either/or terms. We need a comprehensive strategy that involves both women-oriented programming as well as integrating women into existing programmes, both agenda-setting activities as well as those that incorporate women into mainstream structures (Anderson, 1993). It is this comprehensive approach that must be captured for the benefit of the CIHR. Women's health research, plus the issues of sex and gender require a combination of approaches from both of the first two options.

## ■ VI. ILLUSTRATIONS OF THE ENHANCED WOMEN'S HEALTH RESEARCH INSTITUTE

As the following illustrations demonstrate, a Women's Health Research Institute with a gender mainstreaming component would lead to inclusive, integrated, comprehensive and scientifically rigorous research in the selected text areas of Cardiovascular Disease (CVD), Osteoporosis, and Violence. Improved health for women and benefits to families and communities would result. Tremendous cost savings to the health care system would be realized. A Women's Health Research Institute focusing on both sex and gender related aspects of women's health and with a catalytic and educative gender mainstreaming component would be a crucial mechanism for achieving these results. In addition, we list areas in which the Women's Health Research Institute could collaborate with other institutes to produce research. CVD, Osteoporosis (bone health), and Violence are but three of many areas in women's health which need further investigation and integrative health research responses.

### a) Cardiovascular Disease

Traditionally, most CVD research has been focused on men but generalized to the female population. CVD is the leading cause of death for Canadian women: 41 per cent of all deaths of Canadian women are CVD related, compared to 37 per cent for men (Heart and Stroke, 1997). It is increasingly apparent that diagnostic indicators, symptoms, disease etiology, prognosis, treatment, and recovery are very different for women. It is also becoming apparent through the study of animal models that there are significant sex differences in the

developmental biology of cardiac muscle and cardiac electrophysiologic systems (Leblanc et al., 1998). Little research has been undertaken to explore the reasons for these or their clinical implications (Doyal, 1998). Studies have shown, however, that women are not diagnosed and treated as aggressively as men (Krumholz, Douglas, Lauer, Pasternack, 1992). Women reporting symptoms are often told they are imaginary or psychosomatic. The Heart and Stroke Foundation of Canada (1997) has recommended that research funding should be made available to address gaps in knowledge regarding women, heart disease and stroke commensurate with the significance of the issue.

## Cardiovascular Disease

| | |
|---|---|
| **Sex specific** | |
| testing of screening and diagnostic tests whose efficacy is unknown for women | A |
| examination of women's unique CVD symptoms | A |
| investigation of CVD as postmenopausal disorder including investigations into hormone therapy | B, A |
| the effects of hypertension in the development of CVD | B |
| the relationship of oral contraceptives and pregnancy on CVD | B, A |
| unique sex-specific risk factors, prognostic indicators, complications, and higher causes of mortality from heart attacks for women under the age of 50 | A, H |
| **Gender** | |
| Education | S |
| perceived lack of control over home and work, occupational causes of heart disease | S |
| access to health care | H, S |
| gendered responses of practitioners | H, S |
| studying differences *between* women without necessarily contrasting women and men allows for a fuller understanding of the differences *among* women. | A, S |
| why Aboriginal women experience higher death rates than the general Canadian female population for both ischemic heart disease and stroke | A, H S |
| why South-Asian women have an excess of prevalence of CVD. | A, H, S |
| **Gender Mainstreaming** | |
| disease prevention (smoking cessation, increased exercise, low-fat diet, aspirin, alcohol) | B, A, H |
| help-seeking patterns | H, S |
| bypass surgery recovery patterns | A |
| coronary artery disease rehabilitation | A, H |
| anatomic and electrophysiologic differences in cardiac function | B, A |
| differences in fibrinolytic protein activities | B, A |
| risk factor investigations (blood lipid profiles, hypertension, diabetes, and obesity) | B, A |

**Legend**

**B -** Basic Biomedical

**A -** Applied Clinical

**H-** Health Services & Systems

**S-** Social & Cultural Dimensions

**"The ambiguity and confusion about appropriate language speaks of a larger ethical problem of how it is that sex difference has been conceived, studied, and addressed in biomedicine." (National Institutes of Health Agenda for Research on Women's Health for the 21st Century, 1999: 18).**

**Benefits**

The integrated approach to investigating CVD would lead to more accurate and comprehensive information as to why many aspects of risk factors, clinical presentations, therapeutic choices and outcomes of CVD are different for women and men. There would also be potential for tremendous cost savings by reducing the current cost burdens of CVD in women. In Canada, direct costs were calculated to be $3.43 billion/indirect costs $4.72 billion in 1993 (Heart and Stroke, 1997).

## b) Osteoporosis (bone health)

Osteoporosis, which involves the weakening of the body's skeleton because of a loss of bone density, affects women disproportionately. The condition is eight times more prevalent in women than in men (Haseltine, 1997: 132) and makes women susceptible to fractures of the hip, spine and wrist. Women are at greater risk for osteoporosis and osteoporotic fractures than men because they have less bone mass to begin with and following menopause, loss of bone mass accelerates (Collins et al., 1994). A woman's risk for hip fracture is equal to the combined risk of developing breast, uterine and ovarian cancer (Finnegan, 1996: 292). Thin, small-boned women of European or Asian descent are at especially high risk (Haseltine, 1997: 10). Osteoporosis has sex and gender specific manifestations, etiology, impact and outcome of treatments. To reduce suffering and disability, research is required to help prevent the disorder, diagnose it earlier to minimize its effects and to provide interventions to maximize functioning in women patients who have osteoporosis (NIH Agenda, 1999).

| Osteoporosis (bone health) | |
|---|---|
| | |
| **Sex specific** | |
| links between amenorrhea and osteoporosis | B, A |
| premature menopause | B, A |
| abnormal sex chromosomes | B |
| role of estrogen replacement therapy in slowing bone loss in older women especially estrogen's effect in calcium absorption, bone growth remodelling | B |
| why women of colour less susceptible to disease | B, A, S |
| calcium supplementation, and exercise in preventing osteoporosis and fractures in postmenopausal women | A, H, S |
| **Gender** | |
| Depression as an increased risk factor of osteoporosis | H, S |
| eating disorders – i.e. the impact of anorexia nervosa, bulimia | A, S |
| **Gender Mainstreaming** | |
| genetic testing to determine who is at risk | B, A |
| high calcium diet in childhood, adolescence and young adulthood – on bone density, walking, running, weight training – early in life | A, S |
| investigations of drugs that build bone mass | A |
| hyperthyroidism and hyperparathyroidism | B, A |
| epidemilogy of fractures | A, H, S |
| use of corticosteroids and anticonvulsants | B, A |
| Diabetes | B, A |
| alcohol consumption, smoking | H, S |

**Legend**

**B -** Basic Biomedical

**A -** Applied Clinical

**H-** Health Services & Systems

**S-** Social & Cultural Dimensions

**"Either one alone is likely to be ineffective. However, much of the innovative research is likely to be generated by an organ-ization that focuses on women's health." –**
**Margrit Eichler, Professor of Sociology, Ontario Institute for Studies in Education, University of Toronto.**

**☐ Benefits**

Osteoporosis reduces the quality of women's lives, limits their activities and contributes to large health care expenses (NIH Agenda, 1999). Not only would research lead to improvements that would benefit women and in turn their families, it could also lead to significant health care expenditure savings. For example, in the United States, the estimated amount spent nation-wide on osteoporosis and associated fractures is around $38 million each day (Nancy et al., 1997).

## c) Violence

Violence against women includes acts of physical and sexual assault, neglect, verbal attacks, threats, harassment and other psychological abuses. The majority of the victims are women. According to the 1993 Statistics Canada Violence Against Women survey:

■ 25 per cent of all women have experienced violence at the hands of a current or past marital partner (including common-law partners); and

- 50 per cent of all women in Canada have experienced at least one incident of violence since the age of 16; and
- more than 1 in 10 women at one point found her life was in danger. (Statistics Canada, 1993: 11-12).

According to 1998 *Statistics Canada Family Violence in Canada: A Statistical Profile*, between 1977 –1996, three times as many women were killed by their spouses as were men killed by their spouses. All forms of violence have damaging short and long term effects on the health of women. In addition to physical injuries, sexually transmitted diseases and chronic pain, women who have been subjected to violence experience higher rates of depression, substance abuse, suicidal ideation and suicide attempts (Plichta et al., 1996). However, the health care sector has been slow to recognize the extent and consequences of violence against women and has not viewed violence as an important health issue (Kinnon & Hanvey, 1996).

## Violence

| | |
|---|---|
| **Sex specific** | |
| unwanted pregnancy | A, S |
| gynaecological problems | A, S |
| STDs and HIV | A, S |
| Miscarriage | A, S |
| pelvic inflammatory disease | A, S |
| chronic pelvic pain | A, S |
| Migraines | A, S |
| irritable bowel syndrome | A, S |
| **Gender** | |
| under-identification by medical personnel | A, H |
| misdiagnosis and inappropriate treatment of violence | A, H |
| links between violence and depression | A, H |
| fear, anxiety, low self-esteem | A, H |
| sexual disfunction | A, H |
| eating problems | A, H |
| obsessive-compulsive disorder | A, H |
| post-traumatic stress disorder | A, H |
| Suicide | A, H |
| social context of violence | S |
| attitudes and values | S |
| isolation and alienation and individual/group vulnerabilities (i.e. Aboriginal women, women with disabilities) | S |
| **Gender Mainstreaming** | |
| health effects of child witnessing of violence | A, S |
| physical injury and permanent disability resulting from violence | A, S |
| physical and developmental effects of violence | A, S |
| links between violence and asthma | A, S |

**Legend**

**B -** Basic Biomedical

**A -** Applied Clinical

**H-** Health Services & Systems

**S-** Social & Cultural Dimensions

**"Co-levering is a very powerful tool. It is a way of providing positive incentives and rewards." - Anne Marie Goetz, Institute of Development Studies/BRIDGE, University of Sussex at Brighton.**

### ☐ Benefits

Violence against women carries with it enormous human and economic costs. It causes pain, suffering and reduced quality of life. Far-reaching short and long term health consequences are now being recognized. Domestic violence is believed to be the most common cause of serious injury to women. The World Bank has estimated that in industrialized countries, sexual assault and domestic violence take away almost 1 in 5 healthy years of life of women between the ages of 15-44 (United Nations, 1995). Integrated research would improve the lives of women and children who suffer severe physical trauma and long term mental anguish. It can also save lives. In addition, research would lead to substantial cost savings. In Canada, selected annual costs of violence against women have been estimated to be at least $4.2 billion dollars annually (Greaves et al., 1995).

## ■ VII. OPERATIONALIZATION OF AN ENHANCED WOMEN'S HEALTH RESEARCH INSTITUTE:

This option draws on the strengths of Options 1 and 2 to most effectively meet the integrated and transformative notions embedded in the CIHR vision (see model). Its operationalization would be a Women's Health Research Institute (WHRI) with an additional mandate to encourage a collaborative and educational gender mainstreaming function. While this latter function would not be measured or evaluated by the Women's Health Research Institute, several key informants stressed the need for the Governing Council of the CIHR to identify sex and gender analyses as criteria in the review process of all Research Institutes.

For example, Dr. Vivian Pinn, Director of the Office of Research on Women's Health at the National Institutes of Health (NIH) says: "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."

This proposal builds on several Canadian recommendations. For example, the Canada-US Women's Health Forum workshop recommendations on Research Methods suggested that "a new special multidisciplinary women's health research initiative should be created" (Canada-USA Women's Health Forum, 1996: 186).

It also reflects the first recommendation of the 1994 MRC Report of the Advisory Committee on Women's Health Research Issues. This body suggested that an advisory committee on women's health research be established to act as national co-ordinating body to promote gender-awareness in research, facilitate networking, and distribute grants for research on high priority problems affecting the health of Canadian women (MRC, 1994).

The enhanced WHRI with a gender mainstreaming component will:

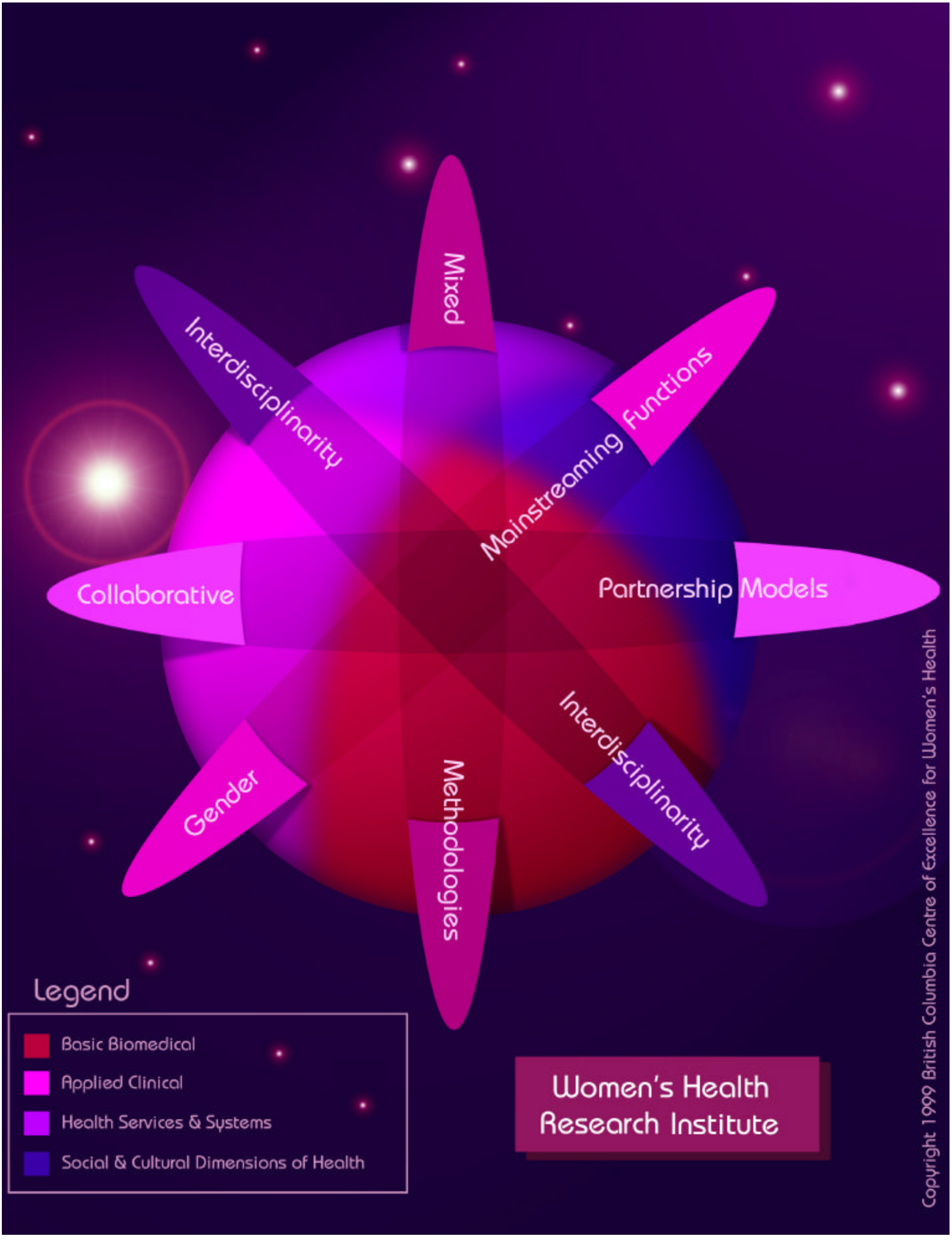
- preserve, locate and enhance sex and gender specific health research on women's health **plus**,
- provide education, support and co-funding opportunities for creative research with and between other CIHR Institutes,
- create synergistic mechanisms for addressing the vast knowledge gaps in women's health research **plus**,
- stimulate interest and develop further capacity for sex and gender differentiated research across Institutes,
- identify issues raised through gender mainstreaming in the CIHR that affect and inform the research agenda in Women's Health,
- foster further development of the integrated model in use in women's health research through capacity building among young researchers and across research Institutes.

Hence, the proposed WHRI with a gender mainstreaming component could be used as an active and evolving example of cross-cutting theme integration, comprehensive interdisciplinary investigation, the operationalization of a holistic view of health, the integration of partnership models into the research process and the inclusion of appropriate mixed methodologies. **Model 1 entitled *Women's Health Research Institute* illustrates this option.**

### ☐ Interactions with other research institutes

The quality of the interactions between Institutes in the CIHR will be the essential indicator of the transformative and integrative aspects of the CIHR vision. The design of the WHRI with a gender mainstreaming function recognizes and articulates the operational aspects of inter-Institute communication and collaboration that are essential to supporting the inter disciplinary nature of women's health research. Second, the focus on gender mainstreaming will allow the accurate and productive application of the concepts of sex and gender to identify and address the elements of research in or between other Institutes that will enhance knowledge regarding both women's and men's health.

Taken together, these two purposes and elements will synergistically create a necessary body of knowledge on women's health as well as a body of knowledge on sex and gender differences. These two elements will



improve the quality of science and health research in Canada in ways that are not currently articulated or pursued in other countries.

Specific functions of the enhanced Women's Health Research Institute:

- build capacity and raise awareness about sex and gender in health research,
- generate and share knowledge about methodological approaches that will enhance integration of CIHR research across Institutes,
- co fund research studies between the Women's Health Research Institutes and other Institutes,
- develop pilot projects in women's health in the first three years to develop Inter-Institute models of collaborative research in CVD, Osteoporosis, and Violence,
- develop and apply a diversity lens to assess the differential and relative impacts of sex, gender, class, ethnicity, ability, age, sexual orientation and geographic location,
- identify and analyse obstacles to women's health research and sex and gender research such as developing inclusivity guidelines for clinical trials and other samples.

**"A women's health research institute could be a resource for the mainstreaming process and could build capacity. The goal would be to expand the vision and lens around women's health." - Stella Lord, Nova Scotia Advisory Council on the Status of Women.**

This proposed mandate and structure reflects an emerging position in the international community that "multiple mainstreaming strategies should be pursued at once, and the potential for synergism among them should be captured" (Anderson, 1993: 11). Additionally, it reflects an evolution from the models of "women's health offices" or "secretariats" as focal points for encouraging and co funding women's health research to a dual purpose research institute on both women's health and sex and gender differences in health research. In our view these two purposes are necessarily interactive and dynamically related. Theoretical and methodological approaches for understanding and pursuing these related research functions are highly developed in the field of women's health research. Finally, women's health research embodies the characteristic elements of successful approaches for developing integrative and transformative research environments that are so critical for the future of the CHIR.

**"If you had a women's institute with a mandate to work across all others and to supply the expertise on women, you get a real multiplier effect." - Dorothy Broom, Senior Fellow National Centre forEpidemiology and Population Health, Australian National University, Canberra, Australia.**

**☐ In the context of other institutes**

**Model 2 entitled *Women's Health Research Institute within the CIHR*** illustrates the relationship between various Institutes and the Women's Health Research Institute in the universe of the CIHR. Institutes are depicted in differing sizes to reflect different evolutionary stages, or different paradigms (e.g. disease models, body system models, population health groups, life course stages, integrative issues, etc). Or, they may be differentially resourced to reflect the magnitude of the health research problems that they investigate or react to, or the capacity for various types of research in Canada. Alternatively, some Institutes may be more inclined to relate to selected others, but not all others, and some Institutes less able to inter relate than others.

To pursue the integrative goals of the CIHR, all Institutes will have, to varying degrees, research in all four cross cutting themes (basic biomedical, applied clinical, health services and health systems and social and cultural dimensions of health and populations). Secondly, all Institutes will relate to a set of operational structures, evaluative mechanisms and challenges that are governed by the council of the CIHR and its Secretariat. These would include guiding elements such as Directorships, Advisory Boards, and review elements such as knowledge transfer functions, gender mainstreaming and peer and ethics review systems. In all, the galaxy image of the CIHR represents the separate but interrelated elements that are affected by the push and pull of variable forces and fields.

Within this, the Women's Health Research Institute is first and foremost a site for integrated scientific research on women's health which will narrow the significant knowledge gap in this area. Secondly, it will analyse its process and serve as an evolving model for developing integrated and transformative research utilizing a mix of disciplines and methodologies. Third, it will inform and be informed by its gender mainstreaming component in


Women's Health Research Institute
Sex and Gender Analyses
Integration of four cross-cutting themes
Operational Infrastructures
Legend
Institutes
Elements supporting research
Partnerships
Knowledge transfer
Co-funding
Human resource transfer
Women's Health Research Institute within the CIHR
Copyright 1999 British Columbia Centre of Excellence for Women's Health

improve the quality of science and health research in Canada in ways that are not currently articulated or pursued in other countries.

Specific functions of the enhanced Women's Health Research Institute:

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developing new research, co funding research with other Institutes and encouraging collaboration between Institutes. Fourth, it will encourage more comprehensive and valid science by encouraging analysis of both sex and gender in all health research across the CIHR.

- **The program in the first three years of operation**

**1. Research Agenda Building**

The Women's Health Research Institute would develop a comprehensive women's health research agenda in consultation with women's health researchers, health researchers from other disciplines (interdisciplinary expertise), health professionals, advocates and consumers. The process of consultation would include educational workshops, public hearings, scientific workshops, national focus groups and a conference in the first year of operation. These activities would allow health researchers from all other Institutes and across the four cross cutting themes to interact and become more familiar with women's health. In addition, it would provide the opportunity for all existing women's health researchers to create an inclusive and collaborative agenda for women's health.

**2. Strengthen Linkages**

During the first year, efforts will also be made to strengthen existing linkages with women's health researchers in the U.S. and internationally. For example, the Women's Health Research Institute would build upon the recommendations of the Canada-USA Forum on Women's Health (1996) to promote further exchange and to advance women's health issues in both countries. In particular, the Institute would build upon the recommendations for joint partnership on key women's health issues. These would include, but would not be limited to, joint initiatives in areas identified at the Canada-USA conference: Breast Cancer, Information Clearinghouses and Networks, Research including Clinical Trials, and Tobacco Use Prevention, focused on Girls, Adolescents and Young Women.

**3. Communications Structures**

The first year of operations would include establishing effective communications structures that provide vital supports for the Women's Health Research Institute. Such structures would encompass knowledge transfer amongst researchers, across institutes, and to the general public. Communication structures will be organized to promote meaningful connection in the form of fax lists, e-mail lists or teleconferences organized according to particular topics. When communicating across Institutes, the Women's Health Research Institute could take leadership in creating cross-Institutes communications linkages on research which has historically been anchored in the women's health movement. Such communication would be structured around the concepts of building collaborative research projects and sharing research experiences in areas of proposal writing, methodology, sample size creation, analysis, and policy uptake. When other Institutes have taken the lead to create networks on subject matter for which there is a body of knowledge in the area of women's health, the Women's Health Research Institute could identify participants for those networks who are able to educate others about issues of sex and gender and their transferability to health research. The Institute will facilitate data transfer by linking with the databases of the newly created Canadian Health Network and its attendant women's health information provider, the Canadian Women's Health Network (CWHN). As well, research findings will be made public on a webpage or in print. The Women's Health Research Institute will work with the Knowledge Transfer Office to dispatch media releases and dissemination of new research reports. In addition, following the models developed in the Centres of Excellence for Women's Health and in the CWHN, briefs will be made available to the most popular sources of health information for Canadian women--women's magazines such as Chatelaine, and to the general public.

**4. Developing Capacity**

The Women's Health Research Institute would also develop linkages with the academic community to develop and mentor young researchers who are interested in sex and gender and women's health research. Drawing on the success of similar programs of one of the outstanding Institutes of the NIH – the National Institute of Allergy and Infectious Diseases, the Women's Health Research Institute would establish an Introduction to Women's Health Research Program. This program would involve partnering young researchers and graduate students with established researchers in women's health. It would involve mentoring, summer placement jobs, and the opportunity to be linked with ongoing research projects of the Women's Health Research Institute and those projects in partnership with other CIHR Institutes. In addition, the Institute would offer career development workshops to graduating researchers to provide them with information about research opportunities in the area

of women's health. The workshops would include an information session about CIHR grants and introduce up-coming graduates to grant writing skills and processes.

**5. Three Pilot Studies**

In the first three years of operation, the Women's Health Research Institute will develop pilot study projects with three (3) partnering Institutes. These projects would tentatively be in Cardiovascular Disease, Bone Health and the Health Effects of Violence, as these are of high priority in women's health and also represent paradigms of health research. In partnership with other collaborating Institutes, barriers and obstacles to undertaking women's health research will be identified. Partnership models and mixed methodologies will be utilized across disciplinary areas. In addition, a plan including policies will be devised for ensuring inclusiveness (attention to sex and gender) in all CIHR research and, where relevant, specifically in clinical trials. Results would be co-published and co-presented at a workshop held in year III. By interconnecting with colleagues from across disciplines and Institutes, the Women's Health Research Institute will develop a model for collaborative, interdisciplinary work. The results of this investigation will be of benefit and interest to all CIHR Institutes.

**6. Resource Allocation**

It is anticipated that at least 50 per cent of the research budget allocated to the Women's Health Research Institute will be allocated to cross Institute co-funding purposes and the other half to Insight and Challenge proposals within the Women's Health Research Institute. In this way, the equal importance of both integrative and specific research will be illustrated.

# ■ VIII. CONCLUSION

The innovative vision of integration and transformation promised by the Canadian Institutes of Health Research (CIHR) will undoubtedly improve both health research in Canada as well as the health of Canadian women and men. In establishing the CIHR in April, 2000, Canada has an important opportunity to integrate and focus upon the issues of sex, gender and women's health. The case for such integration is in the interests of improving the calibre of science, protecting and enhancing the health of 52 per cent of the Canadian population and their families, and launching Canada into an international leadership role in women's health.

The evidence and experience reviewed in this paper supports the conclusion that the establishment of a **Women's Health Research Institute** with an enhanced gender mainstreaming capacity is the most effective operational mechanism for Canada. It suggests a model for reflecting the direction expressed by the Health Minister, the Honourable Allan Rock in the 1999 Women's Health Strategy, "Women's health issues will be promoted in the further development of the Canadian Institutes of Health Research concept" (Health Canada, Women's Health Strategy, 1999: 23).

There is a great deal of research yet to be done to fill the knowledge gap in women's health and to derive important data from gender and sex based analyses in all research areas. There is strong and growing capacity of researchers associated with women's health, and the potential for many interdisciplinary partnerships to emerge in pursuing these research agendas. Women's health research reflects the comprehensive and multi-faceted definitions of women's health that are widely shared across communities. **A Women's Health Research Institute** would provide a focal point for further nurturing and developing the significant existing capacity for such research. It will illuminate a model of integrated, collaborative research that has deep roots in the women's health movement, communities of women and academia. Linked to the other Institutes, and supported by the Governing council of the CIHR, the **Women's Health Research Institute** promises to transform the health of all Canadians.

# ■ APPENDIX A – LIST OF INVESTIGATORS

**Principal Investigator:**

Lorraine Greaves, Ph.D. – Executive Director, BC Centre of Excellence for Women's Health, Vancouver, BC

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Penny Ballem, M.D. – Vice President, Women's & Family Health Programs, Children's & Women's Health Centre of British Columbia, Vancouver, BC

Donna Chow, Ph.D. – Associate Professor, Department of Immunology, Faculty of Medicine, University of Manitoba, Winnipeg, MB, and a Board Member of the Women's Health Research Foundation of Canada Inc.

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## ■ INTERVIEW SCHEDULE

Drawing on your experiences, analysis and "lessons learned":

1. What is your opinion of "gender mainstreaming"?

2. What is your opinion of women-specific policies/programs/institutes?

3. In your opinion, what would the ideal relationship be between gender mainstreaming and women-specific policies/programs/institute?

4. What is your assessment of incorporating women's health issues into a research institute geared to child and family health?

# ■ APPENDIX C – CURRENT FUNDING TO WOMEN'S HEALTH RESEARCH IN CANADA (1997 - 1998)

**NHRDP (Information furnished by NHRDP)**

| | | |
|---|---|---|
| Total NHRDP expenditures on "women's health" 1997/98: | | $4,644,724 |
| Total NHRDP expenditures in 1997/98: N.C.I.C. (Cancer) | | $2,000,000 |
| | Brighter Futures | $618,911 |
| | Seniors | $3,083,203 |
| | National Drug Strat. | $712,723 |
| | AIDS | $905,232 |
| | Regular Program | $11,874,628 |
| | Tobacco | $276,214 |
| | Epid/Public Health | $3,749,476 |
| | **Total 1997/98:** | **$23,220,589** |

**Percentage of funding for women's health in 1997/98:** **20%**

(NHRDP used the following search terms to develop this "women's health" financial profile:
women*, femme*, fertil*, reproductive*, menop*, sein*, breast*, ovar*, uter*, fetal*, pregnancy*, enceinte*, abortion*, avortement*, matern*, osteoporo*, prenatal*, childbirth*, ovair*, foetal*, menstru*, midwifer*, ovul*, fallop*, vagin*, trompe*, pop_sex)

**MRC (Information furnished by MRC)**

| | |
|---|---|
| Investment in Narrowly-defined Women's Health Issues 1997/98: | $19,100,000 |
| Investment in Broadly-defined Women's Health Issues 1997/98: | $64,800,000 |
| MRC's total grants budget: | $156,900,000 |
| Percentage of funding for women's health in 1997/98 (narrow): | **12.2%** |
| Percentage of funding for women's health in 1997/98 (broad): | 41.3% |

Narrowly-defined category includes research related to breast cancer, female infertility, pregnancy/birth and other "gender-specific" headings.

A broader definition of women's health is obtained if we add research investment into conditions which afflict women to a significantly greater extent than men. Examples include rheumatoid arthritis, osteoporosis, lupus erythematosus, Alzheimer's disease, eating disorders and tranquilizer abuse.

**SSHRC Summary of Results:**

| | |
|---|---|
| Women-specific projects: | **18%** |
| Gender Inclusive: | 58% |

**Methodology:**

Emails were sent to one of the researchers on the project team for each of the 54 projects supplied by SSHRC inquiring if they defined their project as research focused on "women's health." If so, how did they define

"women's health" for this purpose and if not, were women included as part of their research sample? Response Rate: 80%

**Data Used for Analysis (information supplied by SSHRC):**

1997/98 Competitions for Standard Research Grants and Strategic Grants: Health Related Issues (Doctoral Fellowships not included in survey due to difficulty in contacting researchers)

**Results:**

| | | |
|---|---|---|
| Health Projects supplied by SSHRC: | 54 | |
| Replies Received: | 43 | (80% response rate) |
| Self-reported as project focused on women-specific health concerns: | 8 | (18% of total replies) |
| Self-reported as including women in samples, gender is analyzed but not the focus of research, or they said if links to gender found during research those links would be analyzed: | 25 | (58% of total replies) |
| Self-reported not focused on women's health or include women in sample size: | 7 | (16% of total replies) |
| N/A (i.e. projects aren't focused on health at all—result of mistakes in SSHRC database.): | 3 | (7% of total replies) |

# APPENDIX D – KEY EVENTS IN WOMEN'S HEALTH IN CANADA

1986 Department of Health and Welfare conducts survey on women's health issues

1987 National Symposium: Changing Patterns of Health and Disease in Canadian Women Establishment of a Federal/Provincial/Territorial Working Group on Women's Health Issues

1990 Publication of "Working Together for Women's Health: A Framework for the Development of Policies and Programs."

1992 Publication of "Breast Cancer: Unanswered Questions, Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women."
SSHRC and Health Canada establish funding for five Research Centres in Family Violence and Violence Against Women

1993 National Forum on Breast Cancer Research and initiation of the Canadian Breast Cancer Research Initiative Establishment of Women's Health Bureau

1994 Canadian Advisory Council on the Status of Women holds a national symposium entitled "Working in Partnership: Working Towards Inclusive, Gender-sensitive Health Policies."

1995 Health Canada announces the establishment of Five Centres of Excellence for Women's Health—identified as a major health challenge in Health Canada's Outlook 1996-97 to 1998-1999

1995 Canada-USA Women's Health Forum

1999 Health Minister Allan Rock releases the Women's Health Strategy

# ■ ENDNOTES

[1]In Canada, women outlive men by six years. See Statistics Canada, Catalogue no. 91-209-XPE, *Report on the Demographic Situation in Canada 1997: Current Demographic Analysis,* June 1998.

[2] A nonprofit corporation of sixteen medical schools, four schools of veterinary medicine and four schools of agriculture, 800 clinical researchers and 100 academic physicians throughout the Association of Canadian Medical Colleges, the Confederation of Canadian Faculties of Agriculture and Veterinary Medicine, the Canadian Society for Clinical Investigation, and the Canadian Institute of Academic Medicine; and 28,000 medical specialists through the Royal College of Physicians and Surgeons of Canada; 14,000 family physicians throughout the College of Family Medicine in Canada.

[3] United Nations Charter 1945, United Nations Universal Declaration of Human Rights, International Covenants on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights 1966, Convention on the Elimination of All Forms of Discrimination Against Women.

[4]Names compiled from: Canada-USA Women's Health Forum; Canadian Advisory Council on the Status of Women; researchers at The Centre for Research in Women's Health, University of Toronto; researchers at the McMaster Research Centre for the Promotion of Women's Health Researchers at Women's Health Office, McMaster University; members of the Working Group on CIHR: Gender and Women's Health Research, Sex and Gender in the CIHR Key Informant List; researchers at the five Centres of Excellence (BC Centre of Excellence for Women's Health; National Network on Environments and Women's Health; Maritime Centre of Excellence for Women's Health; Le Centre d'excellence pour la santé des femmes – Consortium Université de Montréal; Prairie Women's Health Centre of Excellence); researchers at the Alliance of Five Research Centres on Violence (RESOLVE; BC/Yukon Feminist Research, Education, Development and Action; Le centre de recherche interdisciplinarie sur la violence familiale et la violence

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