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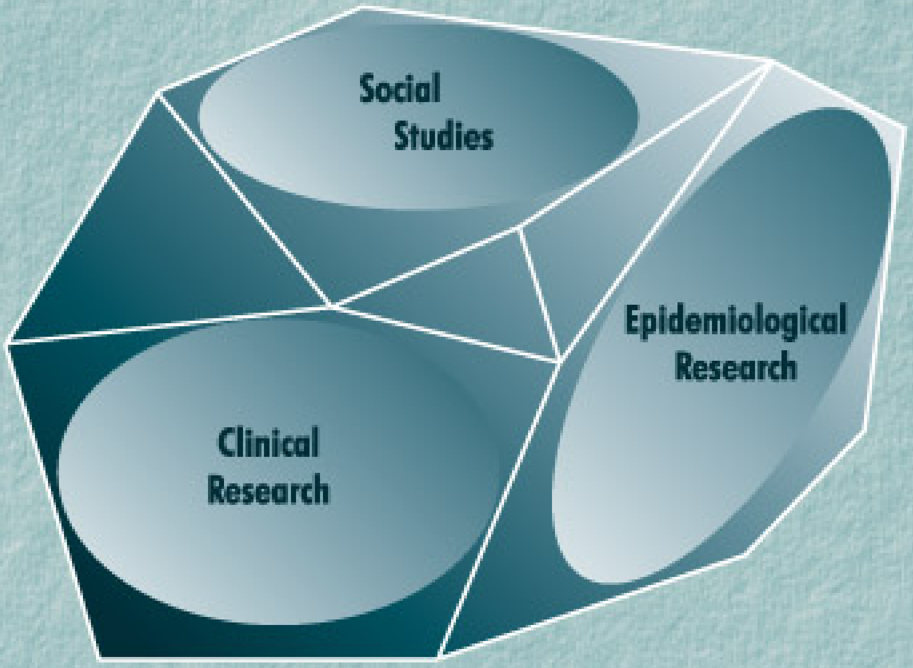
Women's Health Surveillance

A Plan of Action for Health Canada



A Report from the Advisory Committee
on Women's Health Surveillance

Canada

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Health Canada

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A Report from the Advisory Committee on Women's Health Surveillance

Letter of transmittal

Ottawa
August 15, 1999

Dear Dr. Shannon

In reaching our present level of understanding of women's health, results from studies of men have often been inappropriately generalized to women. Not only are women biologically different from men, they also usually differ in the roles and life contexts assigned to them by their particular social settings. As a result, there are important differences between women and men in relation to susceptibility, detection, most effective treatment and other aspects of health conditions.

To improve the health of women, we need to find out the root causes of loss of health — whether genetic, biologic, social, cultural, economic or some combination of these and other factors — and establish a feedback system that lets us move steadily in the direction of more effective prevention, detection and treatment strategies.

The Laboratory Centre for Disease Control (LCDC) has challenged us to provide advice on how such a surveillance system should operate: its issues, priorities, methodologies and potential partnerships in matters of women's health surveillance.

We have divided this work into two tasks. The first is to describe the characteristics of the kind of women's health surveillance system we believe is needed and provide concrete examples of health issues and how they would be handled in such a system. The second task is to see what data are available, what analytic model would be most appropriate, which partners would be needed and what plan of action would permit LCDC to move in the recommended direction most rapidly and effectively.

A series of national consultations were undertaken with experts, researchers and frontline workers. Such a range of participants sometimes leads to counter-productive polarization along researcher-practitioner, social-medical or other axes. This is not what we encountered: the diversity on these occasions resulted in lively debate, a positive atmosphere and a remarkable degree of convergence in thinking. As described in this report, a broad consensus developed around the need for a paradigm shift in surveillance if it is to have a significant impact on the health of women. There was also considerable agreement on how to ensure that the priorities for surveillance remain responsive to changing needs.

Discussions were stimulating, passionate, rich in detail and broad. I would like to thank the members of the Advisory Committee for their wonderful teamwork and their invaluable expertise. My thanks also go to Dr. Elizabeth Dickson, rapporteur for Workshop I. She made every effort to capture the first workshop's major findings so that they could inform the work of the second and third workshops, and as well the Committee's deliberations in taking on the second task — how to put these ideas into action. The reporting from the second and third workshops was done by Caren Uhlik of LCDC; her assistance has been much appreciated. The Committee also greatly benefited from the administrative help of Nicole Cleroux and Brenda Racicot of LCDC. Throughout this project they remained most pleasant, patient and calm, despite the usual last minute crises. Their attention and devotion were unsurpassed. As for Dawn Fowler, my personal thanks for her work on keeping us focused on surveillance while we often wanted to reform and design an entire new system for women's health!

Enclosed are our recommendations and our report, completed by three appendices covering, respectively, each of our three national workshops. To paraphrase the welcoming commissionaire of the Banting building at the last workshop: "They are here for the ladies' issues!"

Monique Bégin

The Honourable Monique Bégin, PC, FRSC, OC
Chair
Advisory Committee on Women's Health Surveillance

The Advisory Committee on Women's Health Surveillance

Chair
The Honourable Monique Bégin, PC, FRSC, OC
Professor Emeritus
Faculty of Health Sciences
University of Ottawa

Members
Sharon Buehler, PhD (joined in March 1999)
Associate Professor, Division of Community Health
Faculty of Medicine
Memorial University of Newfoundland

May Cohen, MD, CCFP, FCFP
Professor Emeritus
Department of Family Medicine
Faculty of Health Sciences
McMaster University

Jean Gray, MD, FRCPC (until March, 1999)
Associate Dean
Continuing Medical Education
Faculty of Medicine
Dalhousie University

Arminée Kazanjian, Dr Soc
Associate Director, Centre for Health Services and Policy Research
Associate Professor, Department of Health Care and Epidemiology
Faculty of Medicine
University of British Columbia

Patricia Kaufert, PhD
Professor, Department of Community Health Sciences
Faculty of Medicine
University of Manitoba

Heather Maclean, EdD
Director
Centre for Research in Women's Health
University of Toronto
Sunnybrooke and Women's College Health Sciences Centre

Donna E. Stewart, MD, DPsych, FRCPC
Lillian Love Chair in Women's Health
The Toronto Hospital and Faculty of Medicine
University of Toronto

Bilkis Vissandjée, PhD
Academic Co-director
Centre d'excellence pour la santé des femmes
Université de Montréal

Secretariat
Dawn Fowler, MA, MUP
Chief, Surveillance Development
Laboratory Centre for Disease Control
Health Canada

Recommendations

In order for Health Canada to discharge its responsibilities in matters of women's health surveillance, we recommend enhancing existing surveillance activity, developing new surveillance systems and creating an infrastructure to support the previous two activities. Specifically, this translates into the following nine recommendations.

1. That the existing cancer surveillance system in LCDC be enhanced as soon as possible in three areas and that the use of gender-based analysis be expanded.
    a) prevention: surveillance of environmental and behavioural exposures, including the work place (e.g., smoking, diet, physical activity, sun-related behaviours, sexual behaviours);
    b) early detection: surveillance of organized and opportunistic cancer screening, including genetic testing, in terms of both access and effectiveness (Pap smear, mammography, colorectal screening);
    c) treatment and supportive care: surveillance of the stage of cancer at diagnosis, access to effective treatment and supportive care, disease-free and total survival, quality of life.
2. That LCDC take the lead on abortion surveillance in Canada, by working collaboratively with all clinics and hospitals that provide abortion services in order to improve the comprehensiveness and quality of reporting. In addition, particular emphasis must be given to the different components of access, including time, distance and availability of services.
3. That the existing LCDC cardiovascular surveillance system integrate in its work a gender-based analysis in the areas of prevention, diagnosis and pathogenesis, management and treatment, and outcomes in order to examine the nature of differences between women and men in heart disease and stroke.
4. As to its monitoring of diabetes, which is also part of cardiovascular surveillance, that a better surveillance system be developed as soon as possible for high-risk populations, in particular First Nations women. Diabetes monitoring should include issues of access, management, outcomes and complications particularly with respect to pregnancy outcomes.
5. That the existing LCDC surveillance of tobacco use in Canada focus on improving data collection for young women aged 12 years and over on both use and determinants of use, and integrate into its work gender-based analysis.
6. That LCDC establish immediately a working group that includes representation from the Canadian Institute for Health Information (CIHI), Statistics Canada, the Department of Justice and other relevant experts in the field to explore, with a

view to development in the near future, surveillance systems for three new areas that were repeatedly identified in the course of our consultation:

- a) muskulo-skeletal disorders, with particular focus on osteoporosis, arthritis and auto-immune diseases, including all significant factors in chronic pain;
- b) mental health, with emphasis on depression, anxiety and self-harm;
- c) violence in its many manifestations and its impact on women's physical and emotional health.

7. That these future surveillance systems, because of their special significance for women's health, be eventually entrusted to a single organizational structure within LCDC.

And to accomplish this,

8. That LCDC establish an organizational structure responsible, at an operational level, for women's health surveillance, which could be a Women's Health Surveillance Bureau with the following double (vertical and horizontal) mandate:
    - a) to complete an inventory of databases relevant to women's health surveillance activities in partnership with Statistics Canada and the CIHI;
    - b) to identify, on an ongoing basis, priorities, indicators and gaps in matters of women's health surveillance;
    - c) to develop and update regularly an index of women's collective health and well-being, i.e., quality of life, analyzed and reported nationally and by vulnerable subgroups;
    - d) to maintain in all its activities a recognition of the diversity of women in Canada, in particular recent immigrants, members of visible minorities, Aboriginal women, lesbian and bisexual women and women with disabilities, in addition to the subgroups of women with particular vulnerability when analyzed in a framework of the various determinants of health;
    - e) to produce an annual report card on the status of women's health in Canada;
    - f) to disseminate its data and analyses to the usual network of partners as well as to a wider network of women's health constituencies;
    - g) to consult and to work in cooperation with Health Canada's interested parties outside LCDC, in particular with the Women's Health Bureau, as well as with Status of Women Canada, in matters of women's health surveillance;
    - h) to facilitate national networking of all interested in women's health on issues concerning women's health surveillance;

i) with the help of Status of Women Canada, to act as an institutional resource for training LCDC's bureaux in gender-based analysis and to monitor its use in all surveillance activities by these bureaux.

This new structure should be given the appropriate authority, financial and human resources, and be held accountable to the Director General of LCDC in the customary manner.

Finally,

9. It is also recommended that an Advisory Committee to the proposed LCDC Women's Health Surveillance Bureau, consisting of outside experts and consumers, be set up immediately to regularly define, evaluate and recommend changes to the priorities and other critical issues for women's health surveillance established through our consultation.

Mandate, Membership and Process

At the request of Dr. Michael Shannon, Director General of LCDC in Health Canada, an advisory committee of volunteer health professionals from across the country known for their work in women's health and representing multi-disciplinary academic and research expertise in the field (medicine, public policy and government, nursing, sociology and anthropology, health economics, epidemiology) started meeting early in 1999. The members were Monique Bégin, Sharon Buehler, May Cohen, Jean Gray (for a time only), Patricia Kaufert, Arminée Kazanjian, Heather Maclean, Donna Stewart and Bilkis Vissandjée. The Committee was chaired by Monique Bégin. An officer of LCDC, Dawn Fowler, acted as Secretary to the Committee, which is known as the *Women's Health Surveillance Advisory Committee*.

The mandate given the Advisory Committee by the Director General was as follows: *"to provide advice on issues, priorities, methodologies and potential partnerships in matters of women's health surveillance. I had asked for your assistance in trying to determine what are the key health issues for women in Canada and indicated that the recommendations from your Committee will serve as the basis for developing a national women's health surveillance system (virtual). (...) a properly designed and comprehensive surveillance system is urgently needed in order to safeguard the future health and safety of Canadian women, especially "high risk" and "vulnerable groups."..."*

In addition to many consultations by telephone, fax and e-mail, the Committee met in Ottawa on the following dates:

- January 7, 1999
- February 1, 1999
- April 8, 1999
- April 30, 1999
- June 3 and 4, 1999

In addition, the Committee held three national consultations, as follows:

- March 29 and 30, 1999: Workshop I, 66 experts and community activists in women's health participated;
- May 28, 1999: Workshop II, in which 16 federal government department experts including the Honourable Hedy Fry, Secretary of State for the Status of Women, and members of the Women's Health Bureau in Health Canada participated;
- June 3, 1999: Workshop III consisted of some 20 analysts and database managers mainly from federal departments and agencies, non-governmental organizations (NGOs) and research institutes, and participants from the private sector.

The following challenges were put to the participants of Workshops I and II: in order to develop a national surveillance system, there is a need to have a list of priority issues for women's health. Aside from listing priorities, the groups were asked why these were priorities and to indicate how to conduct surveillance for each selected priority area. This was an important point made to the groups in support of the notion that women are heterogeneous, and refinement of surveillance is needed to have the greatest impact and thus positive outcomes for women's health. Another challenge for the groups was to develop a method for LCDC to be responsive to changing priorities and to adapt surveillance activities to accommodate these changes.

The experts who joined the Committee in Workshop III were asked to help us with feasibility issues, such as identifying which databases could be used for each priority area and any modifications required. The task of Workshop III was also to note limitations or weaknesses in the existing databases and gaps in terms of providing the information required to undertake surveillance in the identified priority areas. The third main issue of Workshop III was to discuss the logistics in linking various databases and what new data collection activities would be required to address the gaps in the current information available.

What Is LCDC All About?

LCDC is a directorate under the Health Protection Branch of Health Canada responsible for epidemiology, the study of the spread of disease and surveillance of public health issues. LCDC began in 1970 when the Laboratory of Hygiene (which was created in the 1920s), the STD Control Group and the TB Group were brought together within Health Canada. The focus at this time was on infectious diseases. A shift in direction occurred in 1975, when work in non-communicable diseases was undertaken in areas such as cancer and infant and child health. In 1984, work in communicable diseases was redefined with the recognition of AIDS. In 1986, the function of epidemiology was split into communicable and non-communicable diseases, and then in 1990 there was a very serious movement to secure funding for epidemiology.

Today the yearly budget for LCDC is approximately $48 million. The current mission of LCDC is to facilitate effective, evidence-based public health interventions on a national basis through surveillance, field investigations, applied research and timely dissemination of information related to needs, priorities and strategies. Today's mandate of LCDC still follows along the conventional line of surveillance, in that LCDC is accountable for the following:

- conducting or coordinating the risk assessment of diseases and injuries through national and international surveillance, field investigation and applied research;
- active dissemination of timely public health information and evidence-based options for public health information;
- monitoring and evaluating public health interventions; and

- building national capacity for public health interventions through provision of expertise, quality assurance measures, consensus building and partnerships.

A major strength in having LCDC coordinate national level surveillance is its ability to bring together partners from across the country and to work with the international community on issues of surveillance. A critical element for surveillance to be successful is the agreement on standardized definitions and commonality in approach. For this to be achieved, it is important to have an organization that can provide the function of coordinating and bringing the various actors together. LCDC is well situated to fulfil this vital role. In addition, LCDC has a wealth of analytic expertise. It is able to provide analysis of the key surveillance issues and also forecast the impacts of health issues.

What Is Health Surveillance?

Historically, health surveillance was established to prevent and control the spread of infectious diseases. Although infectious disease remains an essential component of health surveillance, more recently, surveillance has expanded into chronic diseases, risk factors associated with diseases, and injuries and other non-chronic events such as abortion or pregnancy. While the scope of surveillance has changed somewhat over time, the principles have not. Health surveillance is the continuous, systematic collection, classification, interpretation, reporting and dissemination of health information.

The purpose of health surveillance is to have an evidence-based foundation for clinical decision making, health policy, program design and evaluation of targeted interventions. By observing trends in time, place and person, changes can be anticipated and appropriate action taken. However, it is also important to note the limitations of surveillance. Health surveillance cannot answer all questions about health and illness nor can all questions be answered by one source of information. Surveillance is not clinical or social science research, nor is it a detailed survey of an “at-risk” population at one point in time. It is the ongoing monitoring and reporting of trends. We must realize that different strategies and methodologies are necessary to be able to achieve a comprehensive picture of an issue. But at the same time, it is also important to ensure that each component of data collection is well designed for its particular strength and is not used for purposes other than what it is intended to do.

Surveillance and Women’s Health

In 1998 LCDC undertook an environmental scan and as part of that exercise conducted a “gaps analysis” of its current surveillance activities. It was determined that there was no comprehensive monitoring and reporting on women’s health, in large part because of the paucity of Canadian women’s health data. This was considered a significant weakness in its surveillance activities. The need for better data and reporting on women's health has been recognized internationally and follows the acknowledgment by the scientific community that disease etiology, symptoms and treatment responses can vary by sex and role and that women have been under-represented in clinical trials and research in general. Although women live longer than men, they suffer greater morbidity and are, in general, less healthy than men. Gaps in knowledge about sex and gender differences in health preclude identification of appropriate policy and program initiatives and therefore effective intervention. It is critical to develop an effective national strategy to enhance women's health. One key component of that would be an effective and efficient surveillance system. This would ensure that women's priority health issues are comprehensively addressed, and such a system would complement the efforts of the Centres of Excellence for Women's Health and the Women's Health Bureau in Health Canada.

Working to Develop a National System for Women's Health Surveillance

The development of a surveillance system would provide baseline data and allow for monitoring trends over time in disease incidence (not currently available except for cancer and cardiovascular health), health-related exposures, behaviours and other social and economic issues, such as abortion and working conditions, that affect women's lives. Having such a surveillance system would also allow investigation of the relationships between determinants and outcomes and thereby aid in identifying modifiable health risks and ensuring health-enhancing strategies.

One issue that has not traditionally been considered a health matter is violence in all its forms, and particularly violence against women. While violence is recognized within some government departments, such as in Health Canada, the general philosophy in many jurisdictions is that it is a "justice" issue. Our consultations confirmed very clearly that issues of violence against women are unequivocally health issues requiring surveillance. This, of course, calls for cooperation among government departments.

To address the needs for women's health surveillance, it was recommended from our consultations that LCDC put in place a process whereby external experts in women's health would be consulted to start the partnership-building between the women's health community and LCDC. A women's health surveillance system would then be a reflection of the advice from those most knowledgeable about women's health. A surveillance system created in isolation without ongoing input from experts would not likely be very relevant or useful.

LCDC is well situated to house a women's health surveillance system, and its role in designing and implementing such a system should be, first, to act as a facilitator in terms of bringing people together, seeking their advice and working collaboratively in defining the parameters of women's health surveillance. Second, LCDC should be the focal point for data collection and analysis. Since LCDC already obtains data from and is working with institutions such as the Canadian Institute for Health Information and Statistics Canada, it is natural to strengthen these partnerships and to look at the feasibility of expanding the type of health information available. Third, LCDC has highly skilled epidemiologists and other analysts who can work with partners to interpret the results of their analyses and together determine their significance.

What We Want Surveillance for Women's Health To Be

The surveillance of women's health has to be based on an understanding that health is complex and multifactorial, that women are a heterogeneous group, and that surveillance is undertaken with the goal of contributing information so that positive changes can be made to improve health status and health outcomes for women. Part of this means going beyond the conventional way of conducting analysis, for example. Traditionally, surveillance data have been reported in table format by sex, age, geographic (provincial/territorial boundaries) region and income. This is no longer sufficient in terms of fully understanding women's health. According to this conventional level of analysis, sex identifies the biologic difference between men and women — it is void of any context. Gender, according to the *Gender-Based Analysis: A Guide for Policy-Making* produced by the Status of Women, *"is the culturally specific set of characteristics that identifies the social behaviour of women and men and the relationship between them. Gender, therefore, refers not simply to women and men, but to the relationship between them, and the way it is socially constructed."* Having an issue interpreted according to sex does not provide the needed information to know how women and men are affected by the same issue; thus there must be a move toward gender-based analysis (GBA).

GBA was strongly recommended in our consultations. Briefly, GBA is a process that assesses the differential impact of policies, practices, interventions or programs on men and women. It compares how and why women and men are affected by these things and challenges the notion that everyone is affected by interventions, policies and programs in the same way (Status of Women, 1998). By looking at the multifaceted context of women's lives, GBA goes beyond simply a biologic/genetic explanation. For surveillance to truly reflect the lives and issues of women, LCDC must be willing to adopt a broadening of definitions of what constitutes health and undertake new approaches to data collection, analysis and reporting.

Understandably, in collecting and analyzing data for surveillance purposes, LCDC has been operating under a "disease, disability and premature death model" whereby trends are established and followed for public health purposes. LCDC has also been concerned by the burden of illness and injury on the limited resources of our health care system. Since 1991 it has published the excellent quasi-annual report entitled

Economic Burden of Illness in Canada. As with most conventional health surveillance worldwide, to capture illness, injuries and abortions LCDC uses the international diagnostic categories of ICD-9, calculating for each category of disease or injury the total expenditures registered by the various components of the health care system. Concepts such as "quality of life" and the pyschosocial impact of disease are absent from this approach and classification system.

It became rapidly apparent to our Committee that this approach could not do justice to the complexity of the "determinants of health model" for women or for men, nor could it account for the truly multidimensional nature of disease. As *Health Canada's Women's Health Strategy* (March 1999) states: "*. . . illness and the threat of death are not the only health-related concerns of women. Quality of life issues are important to them and predispose them to ill health. A 1992 study by Vivienne Walters revealed that 68% of women surveyed said that tiredness was their major complaint. Feeling under stress and experiencing disturbed sleep were other related complaints.*" We applaud Health Canada and the provincial/territorial governments for having adopted a population health strategy based on a wide spectrum of 12 determinants of health, from the biologic and genetic endowment of individuals to their education, income and social status, their social support networks, their employment and working conditions, their housing or their environment. If each of these factors is important in itself, their interrelationship also adds new dimensions to our understanding of the health status of the people of Canada.

To translate a population approach into meaningful women's health surveillance, data collection, development of indicators and analysis of women's health status and well-being becomes a key task. Not only are indicators essential to highlight health — or lack of health — trends, but they also help us understand the dynamics of population health and develop appropriate public policies. For example, good qualitative data have to be seen as credible and to carry as much weight as good quantitative data. The approach to women's health surveillance must be comprehensive and multifaceted. To have real value, indicators of women's health should be reported in a disaggregate manner, broken down by all the significant variables needed to represent the diversity of women's lives in Canada, by regions and subgroups, with emphasis on the most vulnerable of the subgroups.

Through our recommendations, we tried to produce a road map for a women's health surveillance system based on the information from the consultations, our own discussions and on what is currently done in order to guide LCDC in its future planning. The road map contains a list of priority issues — short term, mid-term and longer term — and a justification for their selection. It recognizes that women as a group are very heterogeneous, and calls for identifying which subgroups should be included in the surveillance system, for which issue(s) and why. Finally, we reflected on how LCDC, on an on-going basis, would best be responsive to changing priorities in women's health surveillance and remain accountable within its mandate for the larger concern of women's health status in Canada.

Priorities in Women's Health

When undertaking such an endeavour as we had been charged with, one quickly becomes aware of the enormity of the issue and the complexity of trying to answer what was thought at the outset to be a straightforward question. In our consultation process, we brought together many of Canada's best experts in women's health to seek their advice: those involved in the day-to-day administering of services and programs, activists, researchers, policy and program developers, and health care providers. With their energy and interest, it has been a challenge to limit the priority list into something that is feasible but yet, at the same time, puts forth the challenge to move beyond the status quo and develop a system that will have real impact on the lives of women in Canada.

While there was this backdrop of diversity and different interests of the participants, from all of the workshops there was a very definite emergence of priorities. The reader is strongly encouraged to read the Workshop Reports that follow for the detailed discussion of recommended priorities. What became quickly apparent was the need for strengthening existing surveillance activities, such as those for cancer, heart diseases, abortion and tobacco use. Another priority issue was that LCDC must include in its sources of data for surveillance, non-conventional data, such as qualitative data, as well as different sampling strategies to accommodate the hard-to-reach subgroups of the population. As well, LCDC must target its surveillance activities to the groups for whom the issues are most relevant. Not all issues apply equally to all women, and thus if an issue is more applicable for a certain segment of the population, then LCDC should focus data gathering and analysis on that segment.

To support the work of surveillance of women's health issues, we are recommending that an organizational structure be put in place within LCDC serving as a focal point and at par with LCDC's existing bureaux. It would coordinate analysis and reporting, assist in areas where surveillance is already being conducted and initiate new surveillance activities to address the identified, and over the longer term, new and emerging gaps. To assist this organizational structure, there should be an ongoing Advisory Committee made up of external experts, so that a mechanism exists for providing LCDC with the latest evidence and ensuring that the most current opinions are readily accessible. This group would also work with LCDC to establish criteria for deciding when an issue becomes a priority for surveillance and when existing surveillance of an issue is no longer warranted or is in need of modification. Finally, work must begin on developing surveillance in the following three areas, even though they will take longer to implement: muskulo-skeletal conditions, mental health and violence.

Illustrating the case

We recognize that gender-based analysis can be a difficult concept to understand and even more difficult to implement and conduct. Some examples are provided below to illustrate how health conditions affect men and women differently and the importance of appropriate indicators.

For example, if we take mental health (not at present the subject of surveillance in LCDC), its manifestations are quite different between the sexes. Community surveys of women in Canada reveal that, together with stress and fatigue, depression is consistently listed as their primary health concern. Depression is a major public health problem, and the 1996 *World Bank Report on the Global Burden of Disease* stated that 5 of the 10 leading causes of disability worldwide are mental illnesses (including depression), and they accounted for 25% of total disability and 10% of total burden. The prevalence of depression is equal between boys and girls until puberty, then quickly doubles in women compared with men. This pattern persists until after menopause, when women's rates for depression fall, but never as low as those of men. There are wide variations in female depression rates across Canada, with differences by age, income, ethnic background, education and work. It is recognized that low self-esteem, abuse, harassment and double-duty shifts at home and work also contribute to depression and stress in women.

Another example, also not currently the subject of surveillance at LCDC, is violence. We acknowledge from the start that men can also experience violence and that violence is not just a women's issue. However, half of women in Canada over 16 years of age report violence at some point during their lives. Women are over four times more likely to be injured by their male partner than in a motor vehicle accident. Stalking and harassment after separation are commonplace, and women are more likely to be killed by their partner or ex-partner than by anyone else in the community. Women who are assaulted are likely to sustain multiple injuries, and often suffer prolonged severe psychologic and physical health conditions, such as post-traumatic stress disorder and irritable bowel syndrome. The psychologic after-effects include trauma, fear, insomnia, anxiety, depression and attempted suicide. Forty-three percent of injuries inflicted by partners of women in intimate relationships require medical attention. Dating violence and the sexual assault of young women have been linked to subsequent eating disorders. Pregnancy often marks the beginning of a major escalation of abuse, leading to medical sequelae including miscarriage, low birth weight and psychologic trauma.

Aside from the immediate risks to physical and psychological well-being, violence against women is estimated to cost the Canadian economy at least $4 billion per year in the justice, health, social service and employment sectors. Estimates of the annual costs of medical treatment of abused women in Canada range from over $408 million to $1.5 billion. Estimates of in-patient hospital costs related to violence, in 1991-1992, ranged from $37.8 million to $70.7 million per year.

Abuse of women continues to be underdiagnosed or misdiagnosed by many health professionals, including physicians, despite position papers encouraging education and sensitivity to the issue by the Ontario Medical Association, the Society of Obstetricians and Gynaecologists of Canada, the Canadian Public Health Association, and the *Best Practice Guidelines* from the Ontario Hospital Association. Barriers to detection include health care professionals' lack of confidence in their ability to detect abuse and the "confusing pattern of symptoms", cultural obstacles, and professionals' own beliefs and attitudes.

Let us now look in much more detail at three other health conditions also identified by women as priorities: cancer, chronic pain and cardiovascular diseases.

Cancer in women

Slightly more than one in three women will develop cancer during her lifetime, and more than one in five will die of it. While the cancer incidence overall is greater among men than women, it has greater relative impact on women versus other causes of illness, disability and death. All cancers combined are the leading cause of death and potential years of life lost for women by a wide margin (compared with cardiovascular diseases and injuries).

Some cancers are unique to or more frequent among women because they are female (e.g., uterine and ovarian in the former case, breast in the latter). Others, for example lung cancer and melanoma, have differing patterns of occurrence in women because of differing prevalences of risk factors, which are in turn influenced by complex interrelationships of gender, class and education. Lung cancer is increasing among women and surpasses breast cancer as a major killer. Adolescent girls are the only population among whom smoking uptake is still increasing. Gender differences in exposure are not limited to behavioural risk factors; for example, gender roles influence exposure to pesticides on farms: a man is more likely to be exposed during application of pesticides, using protective equipment, while a woman is more likely to be exposed while laundering pesticide-laden clothing, without benefit of protective equipment.

Women may encounter bias in the diagnosis and treatment of cancer. For example, women with the same symptoms of colorectal cancer as men are less likely to be offered endoscopy, and, since women live longer than men and are more likely to be both poor and without a supportive caregiver in the years when their risk of cancer is greatest, their access to high quality care can be multiply affected. Clearly, there is need for more research on the role of gender in the diagnosis and treatment of cancer, but there is also a need for surveillance not only of the cancer itself, but of access, particularly in view of the offloading of responsibilities for health services from provinces to municipalities to families.

Appropriate surveillance information is critical to developing, targeting and assessing the impact of strategies to prevent, detect and treat cancer and to improve the quality of life of women living with cancer; we use it to assess needs, set priorities and evaluate progress.

But how do we know we have made progress? Historically, surveillance has focused on the cases and deaths; these are practical measures of needs (for services) and can be helpful in setting priorities, but they are late and fairly crude indicators of progress in cancer control. While they describe the impact of the disease fairly well and, to a certain extent, enable crude predictions based on trends in incidence or mortality, incident cases and deaths tell us more about how we have failed to control cancer than anything else. Particularly for prevention and early detection, we need information on the modifiable factors or determinants that can indicate where we can best intervene and, having done so, how effective the intervention has been. This applies to behavioural risk factors relevant to primary prevention and to personal and professional practices regarding screening and early detection.

We also need information about a further series of factors that predispose, reinforce or enable the risk behaviours themselves (whether personal or professional). These can be quite specific, e.g., knowledge about the existence and availability of the test, or quite broad, e.g., socio-economic determinants that affect women throughout the "life cycle" of cancer — exposures, behaviours, access to treatment and support. GBA involves exploring how gender influences all these factors.

A case in point: we know that systematic cervical screening using the Pap smear is effective in reducing invasive cases and deaths from cervical cancer. Even where organized screening programs exist, uptake is lower in populations most at risk: poor, elderly, immigrant and indigenous women. Already advantaged populations may be screened more often than necessary, and high-risk populations may not be adequately screened. In order to correct this situation, we need to know a whole range of things beyond how many women get (or die of) cervical cancer:

- How many women are being screened? What ages are they? Where are they (e.g., rural vs urban)?
- How many women know they are at risk?
- How many women know the test exists, is available, safe and beneficial?
- How many clinics in their area offer the test? How many know what the recommended ages, intervals, etc., for screening are?
- How many physicians offer the test to women after the reproductive years?
- How many women are screened in settings with the recommended information and quality assurance systems in place?
- What is the time delay between an abnormal Pap smear test finding and confirmatory diagnosis, between an abnormal Pap smear test finding and diagnosis/treatment of cervical cancer?

Chronic pain

Chronic non-malignant pain is defined as constant or episodic pain that persists over a period of at least three months. The most common types of chronic pain are headaches, particularly migraine and cluster headaches, neck and back pain, arthritis, pelvic pain, neuropathies and fibromyalgia. Also included in this category are temporo-mandibular joint syndrome (TMJ) and vulvar vestibulitis syndrome (VVS). Back pain has been clearly associated with osteoarthritis, and pelvic pain has been reported to be more common in survivors of sexual abuse. Women are more likely to report persistent pain; persons with persistent pain use health services more frequently.

The National Population Health Survey, 1994-95 (16,989 persons aged 15 and over from across Canada), asked three questions about chronic pain: Were respondents usually free of pain or discomfort? If no, could they describe the intensity as mild, moderate or severe? If no, could they say how many activities their condition normally prevented — none, a few, some, most? In addition, respondents were asked about long-term chronic conditions, disability days and mental distress. Women were more likely than men to report pain (20% vs 15%); prevalence and intensity increased with age. Over all categories of chronic disease, more women than men reported chronic pain and the use of drugs for their pain. Mental distress and sleep disorders increased with intensity of pain in each category and, at each level, more women than men were affected. Pain had more effect on men's daily activities than on women's, but disability days and higher frequency of doctor contact in the previous year were reported by women. Gender differences in coping with pain and in the use of health services have been explored, but much more needs to be known to target services appropriately.

Currently, there is no surveillance of chronic pain in either men or women. The data described above are available from the National Population Health Survey. Hospital discharge data would provide some information on the impact of some conditions (migraine, for example) but not those for which current coding does not designate specific conditions (e.g., TMJ syndrome). Because many of the conditions associated with chronic pain are conditions treated on an out-patient basis, no information is available except through physician billing records where, again, coding presents a problem. Current survey methods may be enhanced with the use of questions developed through the International Association for the Study of Pain.

Very little of the information that needs to be tied to the "health" information, such as life context, gender issues, work, availability and access to care over the life cycle and for subpopulations of women (in particular, disabled, Aboriginal, bisexual and lesbian women) is currently accessible. Some is collected in the census and labour force surveys and in special surveys, but we have no information at all on many of the important aspects of chronic pain. Many of the conditions associated with chronic pain will be identified by unique codes by April 2001, when ICD10/CCI will be available. Until then, the usefulness of administrative data to assess chronic pain in women is limited.

Cardiovascular diseases

Cardiovascular diseases are, after all cancers combined, the number one cause of death among women in Canada, as in most industrial countries; but, contrary to what is observed for men, they do not constitute an important cause of premature death in women. Cardiovascular diseases are rare among young women, unless they have diabetes, in which case estrogen loses its protective effect and the risk is slightly higher than in men of the same age; however, these diseases increase exponentially with age. It is as if women had a younger "vascular age" on average than men. On average, women present with coronary heart disease (CHD) symptoms about 10 years later than men. The total number of deaths of a coronary heart disease origin consequently occur at an older age in women than men. For example, 50% of the cases of myocardial infarction/coronary thrombosis occur before the age of 75 among women versus 75% of the cases in men.

It is believed that the risk factors are the same for both sexes, but it remains to be demonstrated in the case of women. In other words, they are well known for men and are assumed to be the same for women: tobacco use (particularly significant for women — women under age 50 are three times more likely to die of heart disease if they smoke; over the age of 35, tobacco use combined with oral contraceptives increases risk even further); high total and LDL-cholesterol (LDL-C); high blood triglycerides (TG) (some studies show that high levels of TG put women at higher risk than men); high blood pressure; diabetes (women who have diabetes are five times more likely to get heart disease than women who do not have diabetes); obesity (risk is determined by waist-to-hip ratio); and family history. In addition, some risk factors are specific to women: pregnancy hypertension, oral contraceptives and menopause (at menopause, risk of heart disease increases four times). As for the symptoms of cardiovascular disease in women, it is now slowly being established by research that they differ between the sexes.

On the role of socio-economic factors and health determinants other than biologic ones, we still know very little. It seems that there is no difference in heart health and cardiovascular conditions between women in paid employment and women at home. Lower prevalence/incidence rates have been observed in women without partners. Disparity between socio-professional categories has been recorded: between the ages of 35 and 55, women working in offices have the highest incidence. The social status/status of the partner seems to play a role, and it is said that a higher incidence of cardiovascular diseases is found in wives of blue collar workers.

CV investigations are less accurate in women. It is reported that women are not provided with the same treatments as men. Granted, women (and mainly older women) report symptoms and consult later than men, with added risks. In cases of myocardial infarction/coronary thrombosis, the prognosis seems generally less favourable for women. Secondary mortality linked to surgery seems a more serious problem than in men. On the other hand, these procedures are carried out less often on women, and they may have more co-morbid conditions because they are usually older. Women and older patients are significantly less likely than younger patients and men to receive proven medical treatments for cardiovascular diseases.

Reporting

As soon as the first elements of a women's health surveillance system are operational, although still in development, reporting on the health status of women in Canada should also start. Reporting mechanisms represent a fundamental dimension of LCDC's work, and disseminating the information collected and analyzed is an important part of its mandate. This was discussed by the participants in all the workshops. Our Committee also studied with interest the model used by the Canadian Perinatal Surveillance System entitled *CPSS Response Framework – Mechanism for Reporting*.

In the case of women's health, we consider that it is LCDC's responsibility to ensure dissemination of information to a much larger and, to an extent, different audience than that of its various bureaux. Besides the usual list of professional agencies and individuals receiving information, we believe that the public and in particular women in Canada, as a constituency (or rather, as diverse constituencies), must be apprised regularly of their health status. We therefore recommend the publication of what could be called an annual report or report card on the health status of women in Canada, both in general but, more meaningfully, by subgroups, with significance for future public policy and community action.

To do so, as well as to discharge its responsibility for an ongoing evaluation and a review process of women's health, LCDC needs to hear voices that are currently absent from its reporting mechanisms. We have therefore recommended the creation of an Advisory Committee, consisting of experts and consumers sitting in an individual capacity, charged with looking "from the outside in" to keep the women's health surveillance system at the cutting edge of the health issues affecting women in Canada.

Issues of Structure

Our Committee has no intention and no reason for commenting on the present internal structure and organization of LCDC. This is not what was asked of us. But we would have been naïve not to think of the importance of issues of internal structure when devising a future women's health surveillance system. Clearly, LCDC does not need a new structure to enlarge some of its current activities to better serve women and their health, nor to adopt and integrate a gender-based analysis for all its activities. Structural concerns arise, however, because of all that needs to be done that is outside the present organizational model and different from the categories used by LCDC.

On the basis of our collective experience in many different organizational environments, our Committee rapidly came to the conclusion that a “focal point” devoted to women’s health surveillance was essential in order to succeed. Although other structures could be devised, we believe that a Women’s Health Surveillance Bureau with status and resources comparable to the existing LCDC bureaux is the best approach. In our recommendations, we defined in detail the specific tasks of its “vertical” and its “horizontal” mandates, including initiatives of animation, cooperation, consultation and facilitation.

Conclusions

During the six months of the Advisory Committee’s meetings, over 100 persons were consulted on the question of women’s health surveillance, the importance of setting up such a system, its urgency, its feasibility, and what should constitute the priority items for such surveillance activities. The consensus we witnessed was remarkable, and the themes were consistent throughout the discussions. The Committee’s members in turn agreed unanimously and with enthusiasm to the suggestions made, and shared the approaches privileged by the participants in matters of women’s health. We tried to reflect them as faithfully as possible in our recommendations.

For the benefit of women’s health issues — indeed, for the benefit of all — we heard that a disease and injury approach is too narrow and not good enough, and that the framework needed to better understand health is one that includes as full a spectrum as possible of its determinants. We agree.

Although taking into account the sex variable may give us a first ground for documenting the differences between men and women in illness and disability, it is often not sufficient. Only a gender-based analysis, in its capacity to shed light on how health and diseases are socially constructed, can help us capture the context of women’s lives and the dynamics of their health status. We agree.

Although women die of heart diseases and cancers in great numbers, restricting surveillance activities to these well-established medical domains, however well conducted, misses many key health issues and conditions that embody the quality of life of women’s life cycle. Mental health, chronic pain and violence are three such particularly sensitive priorities for women when considering their health. We agree.

We therefore started writing our recommendations by taking into account what surveillance activities related to women’s health that exist in LCDC (cancer, abortion, cardiovascular diseases, tobacco use) could benefit from either a larger definition or more specific concepts and hypotheses. We then identified four key health priorities for women (muskulo-skeletal conditions, chronic pain, mental health problems, violence against women) that we think should be developed in LCDC. We still consider these immediate or short-term endeavours, although we are painfully aware that so much preliminary work is needed that they will take some time to develop and set up. Finally, we identified a series of tasks to be undertaken that are an integral part of good surveillance and reporting.

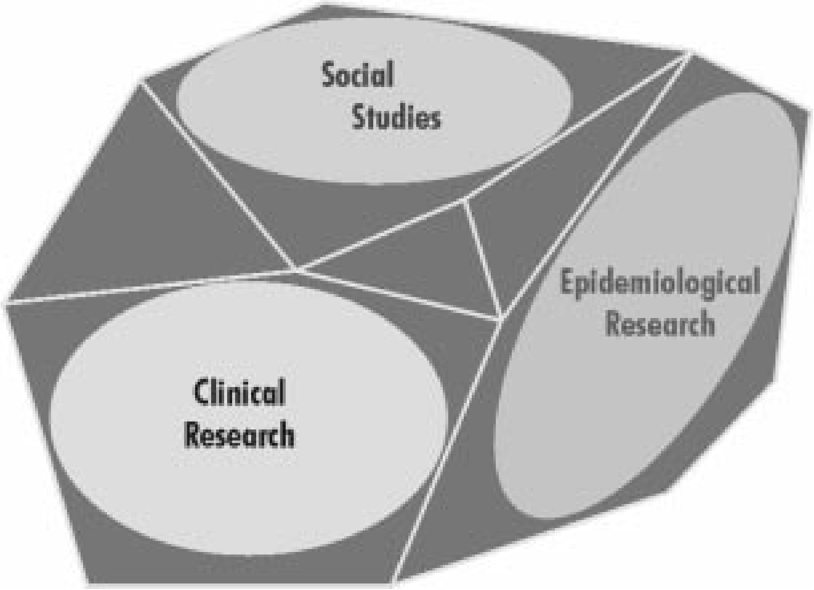
Although LCDC enjoys an excellent pool of analysts and experts, much conceptual work is still needed to arrive at a valid surveillance of women's health. Conventional data collection is insufficient. Surveys and research will be needed. Other agencies, such as Statistics Canada, the CIHI, the Advisory Committee on Epidemiology and the Institute for Clinical Evaluative Sciences, were most positive in their support for a women's health surveillance system within the parameters expressed above, and undertook to help to the best of their ability. In general, the feasibility of what we are recommending was not an issue, they clearly stated. However, between federal government departments as well as between specialized agencies, we noted the lack of working knowledge, cooperation and communication.

Women involved or simply interested in women's health in Canada have high expectations. So much has been said to raise their expectations, yet so little has been done. We believe that a sound surveillance system designed "with women in mind" would meet some of these expectations and form a solid basis for future research, education, public policy and meaningful action.

APPENDIX A

Report of a
Women's Health Surveillance Workshop
March 29-30, 1999
Ottawa, Canada

Women's Health Surveillance:
An Integrated, Multidimensional Approach is Needed



The three-dimensional irregular polyhedron was designed by Dr. Arminée Kazanjian,
Associate Director, Centre for Health Services and Policy Research,
as a graphic representation of the need to integrate information from many disciplines –
including social studies, epidemiological research and clinical research –
to gain a better understanding of the determinants of women's health.

By Dr. Elizabeth Dickson, Rapporteur
Former Advisor to the Secretary-General of the
Organization for Economic Cooperation and Development (OECD)
Former Director of Programs, Medical Research Council of Canada
Sabbatical leave, 1998-99

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Executive Summary

In 1998, when LCDC reviewed its surveillance activities to identify significant gaps, it concluded that a properly designed and comprehensive surveillance system is urgently needed to safeguard the future health and safety of Canadian women, especially "high risk" and vulnerable groups. To get the views of experts from outside government on how to bring this about, LCDC established the Advisory Committee on Women's Health Surveillance with a mandate to provide advice on issues, priorities, methodologies and potential partnerships in matters of women's health surveillance.

Surveillance refers to a *continuous* process of data collection, analysis and dissemination of results. Among the 65 surveillance activities currently conducted at LCDC are four that are specific to women: abortion, breast cancer, cervical cancer and pregnancy. While the present system readily permits health issues affecting the whole population to be analyzed on the *basis of sex* (i.e., by analyzing separately the data for females and males), it does not accommodate *gender-based analysis* (i.e., segregation of data by specific *roles* of females or males in society).

The Advisory Committee adopted a two-phase approach to the task set by LCDC: (1) to describe the characteristics that a women's health surveillance system should embody, how priorities could be arrived at, and how they could be kept current; and (2) to determine the availability and quality of relevant data, consider whether new analytic approaches are needed, and develop a plan of action with recommendations on who should do what to get the system going. The first group of issues was explored at a workshop, held March 29-30, 1999, in Ottawa, with a diverse group of over 60 people from across Canada who are knowledgeable about women's health issues. A second workshop on the ideas and concerns of relevant federal government departments will also be held. A third workshop, with experts on Canadian health-related databases and analysis, will examine second-phase issues. It is on the basis of these consultations and its own deliberations that the Advisory Committee will develop its recommendations to LCDC.

This report summarizes the results of the March 29-30, 1999, workshop.

A broad consensus emerged at the workshop that the surveillance system itself needs to undergo dramatic change. Participants called for a gender-sensitive women's health surveillance system that, ideally, would collect, analyze and integrate quantitative and qualitative information about social, psychologic, economic, demographic, cultural, geographic, genetic, biologic, behavioural and environmental contexts to reveal the most significant determinants and risk profiles for priority health issues; measure the effectiveness of strategies for detection, diagnosis and intervention/treatment; and use the evidence gained to influence federal and provincial government policy across all relevant departments and to empower women.

Particular emphasis was placed on the need to disseminate the results of surveillance rapidly, in readily accessible form, to the public, the health services community and the research community.

"Life context" was seen as a key dimension of surveillance, including factors such as income/poverty, housing, education, work, gender socialization, multiple roles/care giving, stress/violence, diet, support network, spirituality, sexuality, autonomy, access to health services (awareness, distance from services, cultural barriers, language barriers), public portrayal of women and self-image.

Full life-cycle studies were called for to determine the extent to which health has a multiple impact across health issues and throughout a lifetime, including impacts on other family members and society. This requires tracking over time (longitudinal studies), and it is important to note that women's health is not equivalent only to reproductive health but that it spans the life cycle of women.

Recognition of heterogeneity was identified as a fundamental principle of women's health. Because population-wide studies can mask important correlations, analysis of population subgroups — geographic, occupational, age-related, ethno-cultural, for example – was seen as a critical component of women's health surveillance. This raises a set of issues such as the ethics and logistics of recording "race/ethnicity", sexual orientation and disability, and the danger that results could stigmatize population subgroups. Privacy/confidentiality questions in relation to survey information need to be carefully considered. Mechanisms are needed for enabling those being surveyed to have more control in determining what is measured, how it is analyzed, and who has access to the results.

Processes for ensuring that priorities for surveillance of women's health would remain responsive to health trends included the following: (1) that an Advisory Committee on Women's Health Surveillance should be maintained, first, as a multidisciplinary source of advice to LCDC on priorities for surveillance of women's health and the criteria for selecting them, on emerging health-related trends, changing surveillance priorities, and research needs; second, as a two-way link with grass-root communities and the research community; and, finally, as a general overseeing body to monitor the effectiveness of other initiatives to respond to women's health issues; and (2) that there should be a Bureau of Women's Health Surveillance within LCDC to foster research that enhances surveillance methodology, to build partnerships with other government departments and to implement policies that promote public health.

The urgent need for more research on women's health and women's health surveillance, and improved access to information about research and its results was highlighted at the workshop. Participants agreed unanimously that an Institute of Women's Health Research should be included within the Canadian Institutes of Health Research to identify priority research needs, communicate these priorities to research funding-bodies (perhaps in the form of Requests for Proposal) and encourage fasttracking of financial support for women's health research. They also called for a body to be charged with monitoring and making accessible to the public and the research community the results of surveillance activities on women's health issues in Canada.

The importance of strengthening domestic and international linkages to avoid reinventing the wheel and to share data, analytic tools, and best practice in the area of women's health surveillance was a theme that recurred throughout the workshop.

Participants used a number of high-profile women's health issues to exemplify their views about how a women's health surveillance system should operate. They stressed the importance of recognizing that this was not an exhaustive list, nor should it be interpreted as suggesting any ranking of relative importance of the issues. They recommended that a rigorous process for developing criteria and setting priorities be part of the work of the Advisory Committee on Women's Health Surveillance.

Glossary of Terms Used in this Report

Conventional, traditional, alternative or complementary therapies or medicine:

1. **Conventional therapy:** mainstream therapies widely practised in major accredited institutions.
2. **Unconventional therapy:** an approach to diagnosis, treatment and care that falls outside conventional therapies.
3. **Complementary therapy:** an approach to diagnosis, treatment and care used together with conventional therapy.
4. **Alternative therapy:** usually referring to therapies that are used apart from conventional therapy.
5. **Unproven therapy:** therapies that have not been adequately investigated through clinical trials, which can refer to both conventional and unconventional therapies.

   "Complementary and alternative medicine (CAM) can be defined as those medical systems, practices, interventions and applications that currently are not part of the dominant or conventional medical system. There are more than 300 different topics under the term CAM that can be divided into seven major categories on the basis of philosophy, approach to the patient and orientation." (Chez RA, Jonas WB. Am J Obstet Gynecol 1997;177:1156-61.) Jonas is with the Office of Alternative Medicine, National Institutes of Health. These authors describe the seven major categories as the following:

   mind-body interventions (biofeedback, tai chi, relaxation, hypnosis, etc.)
   alternative systems of medical practice (Chinese, homeopathy, Tibetan, etc.)
   manual healing methods (massage, chiropractic, therapeutic touch, etc.)
   pharmacologic/biologic treatments (shark cartilage, ozone, chelation, etc.)
   bioelectromagnetic applications (diathermy, EMF, etc.)
   herbal medicine (feverfew, ginkgo, garlic, ginseng, echinacea, etc.)
   diet/nutrition (folic acid, vegan, soy protein, macrobiotics, Ornish, etc)

Gender: The term "gender" can be seen as the full range of personality traits, attitudes, feelings, values, behaviours and activities that society ascribes to the two sexes on a differential basis. Thus, gender is a social and cultural rather than a physiologic phenomenon. While concepts of gender may differ widely from one group to another and over time, certain features are relatively common. Access to political and economic resources is differentiated by gender in most societies. Power is usually allocated along gender lines and in favour of men.

Gender role socialization: This is the way in which biologic females and biologic males become socialized as women and men, respectively, in any particular culture through learned personal behaviour. Society creates gender roles, and society can alter them.

Health determinant: Health determinants are factors that influence health. These include biology and genetic endowment, health care, education, income and social status, self-image, behaviour/coping skills, personal health practices, housing, employment and working conditions, food/nutrition, environment, discrimination based on culture and ethnic background, powerlessness/degree of control in one's life, and healthy child development (see Presentation i).

Health surveillance: Surveillance is the ongoing, systematic collection, analysis, interpretation and dissemination of information in a timely manner to monitor and improve understanding of the health of those living in Canada. The information is reported at the aggregate level. The purpose of surveillance is to have an evidence base for effective health policy, program decisions and targeted interventions. Examples of health issues under surveillance are abortion, congenital anomalies, breast screening and asthma (LCDC).

Incidence: The number of new events, e.g., new cases of a disease or condition, in a defined population within a specified period of time.

Life context: This refers to the circumstances within which a person lives.

Morbidity: Any departure, subjective or objective, from a state of physiologic or psychological well-being.

Mortality rate or death rate: An estimate of the proportion of a population that dies during a specified period. The death rate in a population is generally calculated by means of a formula in which the numerator is the number of deaths during a specified period and the denominator is the number of persons in the population at risk of dying during the period.

Prevalence: The number of events, e.g., instances of a given disease or other condition, in a given population at a designated time.

Women's health: Women's health involves women's emotional, social, cultural, spiritual and physical well-being and is determined by the social, political and economic context of women's lives as well as by biology. This broad definition recognizes the validity of women's life experiences and women's own beliefs and experiences of health. Every woman should be provided with the opportunity to achieve, sustain and maintain health as defined by that woman herself to her full potential (definition as adopted by the Canadian Government for the Beijing Conference, 1995).

I. Introduction

In 1998, LCDC reviewed its health surveillance activities and found a gap in the area of women's health. It concluded that "a properly designed and comprehensive surveillance system was urgently needed in order to safeguard the future health and safety of Canadian women, especially high risk and vulnerable groups". To assist it in responding to this gap, LCDC established an external group of experts — the Advisory Committee on Women's Health Surveillance — to provide advice on issues, priorities, methodologies and potential partnerships in matters of women's health surveillance.

The Advisory Committee adopted a two-phase approach to the task set for it by the LCDC: (1) to describe the characteristics that a women's health surveillance system should embody, how priorities could be arrived at, and how they could be kept current; (2) to determine the availability and quality of relevant data, consider whether new analytic approaches are needed, and develop a plan of action with recommendations on who should do what to get the system going. The first group of issues was explored by a diverse group of over 60 people from across Canada who are knowledgeable about women's health issues, at the March 29-30, 1999, workshop in Ottawa, which is the subject of this report. A second workshop, with experts on Canadian health-related databases and analysis, will examine the second-phase issues. The results of these two workshops and consultations with key players in federal government departments will be taken into consideration by the Advisory Committee as it develops its recommendations for LCDC.

Discovering biologic and genetic causes of disease has been one of the great successes of the 20th century. When it comes to understanding health, however, this is far from the full picture. As explained by Dr. May Cohen at the opening plenary session of the workshop (see Presentation i), there has been increasing recognition of the significant impact on health of a wide range of social, economic and environmental factors. These, in combination with biologic and genetic factors, help to account for the observed differences in the health profiles of individual human beings and, more generally, between women and men.

The definition of women's health has evolved over the past two decades to reflect this broader view (see Presentation i), leading in 1995 to adoption by the Canadian Government of the following definition as a basis for its discussions at the Beijing Conference:

> *Women's health involves women's emotional, social, cultural, spiritual and physical well-being and is determined by the social, political and economic context of women's lives as well as by biology. This broad definition recognizes the validity of women's life experiences and women's own beliefs and experiences of health. Every woman should be provided with the*

> *opportunity to achieve, sustain and maintain health as defined by that woman herself to her full potential.*[1]

Seen from this perspective, the determinants of women's health go beyond an individual's biologic and genetic endowment to include factors such as health care, education, income and social status, self-image, behaviour and coping skills, personal health practices, housing, employment and working conditions, food and nutrition, environment, discrimination based on gender, culture and ethnic background, powerlessness and the degree of control in one's life, and healthy child development (see Presentation i).[2] [3] [4] [5] [6]

Clinical research, epidemiologic research and social studies each provide some of the information needed to understand the roles and relative contributions of these determinants to health. To date, these research efforts have been largely fragmented along disciplinary lines. As discussed by Dr. Arminée Kazanjian in her presentation at the opening plenary session (see Presentation ii), a multidimensional approach that integrates results from these and other disciplines is needed to achieve a significant advance in the understanding of women's health.

II. The Nature of Health Surveillance at LCDC

LCDC, a Directorate of the Health Protection Branch of Health Canada, is Canada's national authority for public health. Originally established to prevent and control the spread of infectious disease, LCDC in recent years has extended its focus to include chronic disease and injury. As described by Dawn Fowler in her remarks at the opening plenary session (see Presentation iii), LCDC is accountable for

- conducting or coordinating *assessment of disease and injury risk* through national and international surveillance, field investigation and applied research;
- disseminating timely *public health information* and evidence-based options for public health intervention;
- monitoring and *evaluating public health interventions*; and
- building *national capacity* for public health interventions through provision of expertise, quality assurance measures, consensus building and partnerships.

The term "health surveillance" is reserved for the highly specific *ongoing* activity of systematic collection, analysis, interpretation and dissemination of information to monitor and improve understanding of health. Information is reported at the *aggregate* level only. LCDC surveillance of 65 or so health issues — including, for example, abortion, congenital anomalies, breast screening and asthma — provides an evidence base for effective health policy, program decisions and targeted interventions. To illustrate in a concrete way what health surveillance at LCDC entails, the example of therapeutic abortion is presented in the box. The five indicators listed are calculated and reported either monthly or annually. Demographic fertility data are drawn on together with data from clinics and hospitals about the number of abortions, age of pregnant women and gestational age.

Health surveillance is a complex task requiring a sound analytic model capable of extracting useful observations from diverse data sources, including specific surveys, administrative databases and data contained in reports of relevant studies or research. The introduction of new variables to be measured is usually accompanied by significant costs for the collection of data, amendment of the analytic model to accommodate the new variables, and design of new ways to combine variables to produce improved indicators for tracking health issues of interest. To apply available resources in the most effective way, it is therefore essential to set priorities among the various health issues and identify the kinds of information likely to produce insights with the greatest impact on the health of populations.

Example: Abortion

WHAT IS CURRENTLY DONE

Indicators reported on a monthly or annual basis:

1. Number of therapeutic abortions per 1,000 women in the age range 10-54, broken down by age group. Note that for teens, it is more useful to have ages 10-16, then separate figures for 17, 18 and 19 year olds (traditionally the age group is 15-44; however, there are women as young as 12 and as old as 48 in the pilot). Menopause age average is 52 years. For international comparison, the age group 15-44 should be able to be isolated from the 10-54 report.
2. Number of therapeutic abortions per 100 live births (although it may be logical to report per stillbirth and live birth, this is the indicator used in other reporting systems).
3. Frequency of use of different procedures used to do the abortion, e.g., medical/pharmaceutical abortion, manual vacuum aspiration, dilatation and suction, use of laminaria, intra-amniotic injection.
4. Number of therapeutic abortions at various gestational ages, e.g., < 8 weeks, 8-12 weeks, 13-16 weeks, 17-20 weeks, > 20 weeks.

Also reported commonly:

5. Complication rate.

IDENTIFIED GAPS

Issues raised by workshop participants to be included in surveillance, which were also raised at the National Abortion Federation meeting:

1. The time from when the decision is made to have an abortion to when services are received
2. The distance required to travel to obtain abortion services

III. Characteristics That a Women's Health Surveillance System Should Exhibit

Participants at the workshop were united in calling for a fundamental paradigm shift in women's health surveillance in Canada, to move "out of the box", away from the disease model; to recognize what we *do* and *do not* know; to find new ways to obtain knowledge about women's health that lets us do something about it; to think beyond measuring; and to begin looking at the interactions among the different influences.

For many, the example of surveillance of therapeutic abortion was a first exposure to the practical details of the Canadian health surveillance system. Recognition of the value of what is already being done was accompanied by surprise at the limited nature of the indicators — no qualitative information, little insight into women's health, and no analysis of issues such as geographic distribution, barriers to health service access, or time elapsed between seeking and receiving health services.

To function effectively, the health surveillance system envisioned by workshop participants would need to i) broaden the approach to identifying and tracking the determinants of health; ii) revise the analytic model to accommodate this expansion and to reflect an integrated approach to understanding health; iii) be supported by a more strategic approach to research on women's health and its surveillance; iv) strengthen linkages within Canada and abroad to avoid reinventing the wheel; v) disseminate results rapidly in forms accessible to a wider range of recipients; and vi) establish a consultative process for setting surveillance priorities and keeping them current.

Three tables are given listing the health issues that participants identified as requiring further elaboration in terms of surveillance, issues that are of interest, and issues to constitute the development of a framework for surveillance.

Table 1 - Health Issues Elaborated by Groups

- Cardiovascular diseases/conditions
- Depression/Mental health/Stress
- Abusive relationships/Violence
- Reproductive choice/Abortion
- Eating Disorders/Fitness/Body weight
- Substance abuse/Smoking
- STDs/HPV
- Osteoporosis/Musculoskeletal
- Chronic, non-malignant pain/Arthritis
- Breast cancer
- Diabetes
- Dementia/Alzheimer

Table 2 - Health Issues Of Interest

- Chronic fatigue syndrome
- Injuries
- Female genital mutilation
- Issues of pregnancy/C-section
- Breast implants
- Tuberculosis
- Fetal alcohol syndrome
- Breastfeeding
- Suicide
- Medication use/abuse
- Menopause
- Nutrition
- HIV/AIDS
- Alternative therapies
- Infertility
- Cancer
    - skin
    - lung
    - cervix
    - ovaries
- Occupational health
- Autoimmune diseases
- Self-care
- Parenting

Table 3 - Issues of Conceptual Framework Nature

- Heterogeneity is an essential dimension of health. Hence surveillance should identify the most vulnerable subgroups:
    - Aboriginals
    - Poverty/Economic vulnerability
    - Women with disabilities
    - Isolation
    - Lesbians and bisexuals
    - Immigrants
    - Adolescents
    - Elderly women
- Monitor gender differences in terms of diagnosis/detection and therapy towards ensuring appropriate use of technology/genetic testing.
- Need to capture the multiple roles of women and the impact on their health:
    - How women spend time
    - Unpaid work at home
    - The care giving role
- Consider the full life cycle, including deaths.
- Importance of quality of life issues in women's health — often high morbidity, low mortality and high incidence in women, e.g., lupus.
- Surveillance must somehow integrate data covering the spectrum of the determinants of health. Important to draw on international leaders in achieving this (e.g., UK).
- Accessibility to information, services, etc., should be tracked in relation to health status. That involves cultural or linguistic barriers.
- Need to establish links between women's portrayal, how they see themselves and the impact on their health.
- Does de-institutionalization affect women's health differently?
- Does health care reform affect women's health differently?
- How should "economic burden" apply to women's health?

i) Broadening the approach to identifying and tracking the determinants of health

Concern was expressed that the narrowness of the medical or disease model traditionally applied to shed light on the origins of poor health prevents identification of important health determinants. As a result, scarce resources may be allocated to approaches to health care that are much less effective than they could be. For example, in the case of some mental illnesses, addictions, stress-related conditions or eating disorders, factors such as self-image, social support network, total burden of work (paid and unpaid), physical or mental abuse, coping skills and relative degree of control in one's own life, to name just a few, may be more influential, either alone or in combination, than the biologic/genetic endowment of the individual. Only by identifying these through measurement and analysis can the effectiveness of strategies for health promotion and for prevention, detection, diagnosis and treatment of poor health be improved.

Participants put forward a wide range of health determinants and risk factors to be considered alongside those monitored in the existing surveillance system, underscoring the need to collect both quantitative and qualitative information. While it would be a formidable task to measure all of these in relation to all health issues across the board, this was not the intention. Rather, this list is intended to indicate the broad context within which women's health should be understood, with an expectation that methodologies will evolve to identify more and more effectively the most influential determinants for each health issue tracked in the LCDC surveillance system. A summary of the broadened set of determinants and risk factors discussed by participants is presented below, grouped under the headings (a) life context, (b) gender, (c) work, (d) health care, (e) life cycle and (f) subpopulations.

(a) **Life context**: The circumstances within which a woman lives can play a major role in susceptibility to poor health. This would include but not be limited to quality of housing, food, water and air; ease of access to education, information about health, and health services; degree of support obtained through family, friends or community networks; ways in which time is spent and who controls it; ease of access to and degree of control over resources (to meet basic needs); and society's portrayal of women and its impact upon self-image and health practices.

(b) **Gender**: The existing health surveillance system permits analysis of differences between females and males in relation to health issues. However, this is strictly on the basis of biologic sex. Workshop participants emphasized the importance of extending this to an examination of the differential impacts of gender roles — the specific female and male behaviour patterns attributable to cultural setting. Since gender roles are learned, they have the potential to evolve in a direction that is more supportive of good health in response to a clear link between existing gender-specific behaviour and risk of poor health. The high priority placed on this dimension of women's health surveillance is parallelled in a recent report focusing more broadly on gender in relation to public policy in Canada.

(c) **Work:** A woman's health can be profoundly affected by the type of work she does, the total burden of work, and the psychological environment of the work. Participants of the workshop were particularly concerned that ways be found to measure the *total burden of work* for individual women and to assess its impact on her health and the health of her family. It is expected that, for many women, the burden of multiple roles is increasing as a result of trends to devolve care from institutions to families, increased presence of women in the paid work force, and the increase in numbers of households headed by single women, accompanied by the ongoing traditional roles as homemaker, community volunteer, manager of family health, and caregiver for children, spouse, elderly parents and friends.

These concurrent responsibilities can lead to chronic insufficient sleep, and anxiety and guilt associated with feelings of inadequacy in performing each of the multiple roles, leaving little time for self-care such as exercise, attention to nutrition or health care. In turn, this situation may increase susceptibility to conditions such as heart disease, depression, auto-immune disease or cancer. The surveillance system needs to measure the multiple work profiles of women and identify links with mortality, morbidity, family structure and socio-economic status. This will require development of models for measuring the "invisible" roles — unpaid work, care giving, homemaking, volunteer community service.

The *care giving* component needs to be better understood to ensure that public policy keeps step with changing trends such as demographic factors (increasing proportion of the population in the 65+ age group), changes in health care systems (devolution of care to families), and other trends such as increased years of dependency of children. Among dimensions needing attention are gender, age, ethno-cultural setting, geographic area (rural, urban), economic status (poverty), education, family structure and access to services. The women's health surveillance system should measure how much care giving is being transferred from institutions to families, the health impacts of this transfer and the full costs to society.

The type of *paid work* can also present important health risks. The hours of work can range from excessive to disruptive (e.g., shift work), to not enough (part time work, links to poverty). The work environment can be physically or mentally hazardous through factors including pollution, unsafe equipment or materials, abusive relationships, or chronic uncertainty about the security or value of an individual's work.

Self-care may be seen as the most critical of a woman's multiple roles since incapacitation through neglect interferes with the whole spectrum of work normally performed, including the role of "health director" for the extended family. Ironically, self-care is also often the task attended to last, if at all, by an overburdened woman. Public policy strategies to assist by providing more information to women about how to access health care may be largely ineffective if the main barrier is time, not information. To shed light on this issue, it will be necessary to monitor use of health care services and link use or non-use to the health status of women and their extended families.

(d) **Health care:** Timely access to services for prevention, detection, diagnosis and treatment of poor health is a key determinant of health. Participants in the workshop emphasized the need to focus on quality of life, alongside mortality and morbidity, as a criterion for assessing health care strategies. They also highlighted the importance of allocating public funds to the most effective interventions. To achieve this, knowledge about the relative merits of the full range of options is needed, drawing upon the best evidence from conventional, traditional, complementary and alternative medicine, and harnessing the best information available from surveillance systems and research communities in Canada and abroad. Recognizing that 30% of Canadians include alternative, complementary or traditional approaches in their health regimens, surveillance should document this trend, identify the most frequently used practices, study safety and efficacy, contribute to development of a quality control system, and ensure that information about the benefits, risks and protocols for use of these practices is readily available to consumers. Expansion of over-the-counter alternatives to prescription medicines, based on evidence derived from rigorous surveillance, could have important impacts on health both by increasing an individual's control in managing personal and family health and by reducing pressures on public health services.

Ensuring *appropriate use of technology* needs particular attention. Concerns emerged at the workshop about possible overuse of some technologies (e.g., ultrasound imaging in pregnancy, Cesarean section deliveries), underuse of others (e.g., angiography), and the need for standardized guidelines to ensure safety and equity of access to technologies such as mammography, Pap tests, bone density measurement, screening for colorectal cancer, and technologies that facilitate reproductive choice.

Genetic testing was singled out for special consideration because of its potential for broad application and its linkage to complex medical, ethical, legal and social questions. Participants saw a need for surveillance to ensure early detection of emerging trends and assessment of their impact on women's health — for example, what genetic testing is being done and how frequently. Is genetic testing affecting therapeutic abortion rates, access to insurance, employment opportunities, relationships, mental state or general state of health? What are the rates of false negatives and false positives and what is their impact? Is there equity of access to genetic testing? Is appropriate counselling offered? The surveillance system needs to examine such questions and use the results to improve the effectiveness of genetic counselling services, identify issues requiring further research, promote development of increasingly reliable tests, and stimulate a knowledge-based public dialogue on the psychological, ethical, legal and social issues arising.

Accessibility of health care can have a major impact on health. Physical distance from services, personal beliefs, cultural setting, mobility, socio-economic status, age, gender-specific roles, and deficiencies, gaps or overloading of the health care system can all affect an individual's access to health services. Identification of these barriers is an important function of a women's health surveillance system, so that public policy, informed by these results, can move continuously in the direction of more equitable access across the population.

Cost-effectiveness information is critical, particularly in times of constrained public budgets, to ensure that incentives in the system and policy guidelines move health care practices steadily in the direction of greatest improvement in health for a given expenditure.

(e) **Life cycle**: Participants observed that, in the past, study of women's health issues has been disproportionately focused on the reproductive years and has provided little opportunity for understanding the influence of one health condition on another over a lifetime. Full life cycle studies (longitudinal) were called for to determine the extent to which health impacts interact and become additive throughout a lifetime, both on the individual affected and on other family members and society. Cross-sectional studies of all phases of the life cycle, not restricted to the reproductive years, are also needed.

(f) **Subpopulations**: Recognition of heterogeneity was identified as a fundamental principle of women's health. Because population-wide studies can mask important correlations, analysis of population subgroups, as defined by geographic factors, occupation, age, ethno-cultural background, family structure, sexual orientation or physical status, was seen by participants as a critical component of women's health surveillance. Subgroups discussed in the workshop included Aboriginal/First Nations women, immigrant women, adolescents, post-menopausal women, single parents, lesbian/bisexual women, women sharing a particular set of beliefs (spiritual) and women in specific geographic regions. Surveillance of clusters of health issues affecting each of these groups could yield important insights for improving health. Focus on subpopulations raises a set of issues such as the ethics and logistics of recording "race/ethnicity", sexual orientation and disability, and the danger that results could stigmatize population subgroups. Questions of privacy and confidentiality in relation to survey information need to be carefully considered.

Another important issue is how to enable those being surveyed to have more control in determining what is measured, how it is analyzed, and who has access to the results. At the closing plenary session of the workshop, Dr. Judith Bartlett from the Aboriginal Health and Wellness Centre of Winnipeg explained the need for participation by Aboriginal peoples in determining research questions, data analysis, dissemination of results and development of policy and programs.

[A statement made in the closing plenary session of the workshop by Judith Bartlett, M.D., of the Aboriginal Health & Wellness Centre of Winnipeg, Inc.]

"There needs to be a separate or enhanced surveillance system for Aboriginal peoples, particularly Métis, non-status and off-reserve First Nation people. There are no data available except for those that are extrapolated from on-reserve First Nations. The approach to issues and concerns as expressed by the mixed group of women participating in this Workshop is not relevant or contextual to Aboriginal women (for example, the discussion of fatigue or stress). The approach to the disease entities must be holistic; data needs to be collected with an Aboriginal framework and owned by Aboriginal people. Several years ago a National Aboriginal Women's Conference held in Winnipeg clearly reported that they did not want to discuss specific diseases (need to be holistic and look at root causes), nor did they wish to discuss women's health in the absence of a discussion of men's health. Analysis of Aboriginal data must not be undertaken without Aboriginal participation — at all levels — from initial determination of research questions to data analysis, dissemination and resultant policy and program development. Additional rationale for specific focus and control of Aboriginal data lies with the constitution."

More generally, participants emphasized the need for two-way communication between the surveillance system and women, facilitating both access to the results of surveillance and feedback to the system.

ii) Revision of the analytic model to accommodate broadened determinants and reflect an integrated approach to understanding health

Analysis of data gathered through a women's health surveillance system, broadened as detailed above, faces many challenges. Participants called for a move away from the disease model toward a model placing greater emphasis on the impact of health issues on the quality of life — a multidimensional approach to analysis, integrating relevant information from diverse sources and producing a "3-D" picture of women's health. The revised analytic approach needs to be able to assess quantitative and qualitative information; cross-sectional and longitudinal data over the full life cycle of women; and the impact of interactions among various health determinants and risk factors. Participants stressed the importance of taking an inclusive approach to the collection of data, with a more selective approach to determining which data would be subjected to analysis at any particular time. This would permit re-evaluation of issues as new insights are revealed.

New concepts and analytic approaches may have to be developed in the case of some of the health determinants and risk factors in the broadened set (e.g., gender roles and unpaid work). Privacy and confidentiality issues need to be carefully considered, particularly in relation to analysis of subpopulations. Consultation and dialogue with representatives of these groups need to become an integral part of the evolution of the analytic systems.

Taking all of these dimensions into account, the relative merits of interventions — to promote health or to prevent, detect, diagnose or treat poor health — on quality of life, mortality and morbidity must be assessed and the cost-effectiveness determined. In combination, results from these analyses should permit health care (including self-care) to move steadily in the direction of more effective approaches. It is expected that significant progress toward the ideal system envisioned by participants at the workshop can be achieved by new approaches to linking and analyzing existing data.

iii) A more strategic approach to research on women's health and its surveillance

The broadened, more integrated, surveillance system described will need to be supported by research on a wide range of issues concerning women's health. As priorities for surveillance are set, gaps requiring more research should be identified and fast-tracked. This includes research on root causes of poor health and on surveillance methodologies. To facilitate a more strategic approach, an overview of relevant on-going research and stronger links between the surveillance system and researchers are needed. LCDC should reach out to the research community on a more regular basis to meet its needs, particularly in the areas of research needed to underpin innovation in the surveillance system methodology. Funding bodies should seek ways to fast-track key research into the root causes of poor health in women and to stimulate better integration across the disciplines (social, psychological, biologic, medical, behavioural and economic) in research projects.

In the only vote taken during the course of the workshop, participants unanimously supported a call for a Women's Health Research Institute within the Canadian Institutes for Health Research.

iv) Stronger links within Canada and abroad to avoid reinventing the wheel

Innovations in health surveillance and contributions to the basic understanding of women's health may come from a wide range of players in Canada or around the world. To ensure the wise application of scarce public funds, duplication of effort must be avoided and synergy through partnership must be actively sought. Provincial health systems have pioneered in many directions. Lessons learned need to be understood and built upon. International links are needed to stay abreast of best practices for health surveillance from around the world and research results from the global community.[8]

Strong links need to be maintained with initiatives such as the Federal/Provincial/Territorial Surveillance Integration Design Team to strengthen the infrastructure for health information in Canada, the Canadian Integrated Public Health System (CIPHS) to better capture, integrate and report health data, and the Spatial Public Health Information Exchange (SPHINX) to harness software for analyzing and presenting information from existing databases.[9]

v) Wider, more accessible dissemination of results

Dissemination of results is a key component of health surveillance. A dissemination strategy should be developed that aims to empower women's communities as informed managers of their own health and the health of family members. It should also aim to deliver results rapidly to decision makers in all government departments whose policy affects women's health, and to researchers engaged in examining the root causes of poor health. The dissemination strategy should also have a built-in feedback loop from the users to the providers of the information.

Lack of awareness of the causes and symptoms of poor health, recommended treatments and how to access them was identified as a key barrier to improving the health of Canadian women. An integrated picture of women's health is needed that can be readily communicated, linking both qualitative and quantitative information from a variety of sources. Information should be packaged and disseminated using various approaches tailored to the different categories of users. For example, it may be useful to prepare separate communication vehicles for ordinary citizens, for researchers and for policy makers. Newsletters and fact sheets presenting trends and detailed updates of individual issues, disseminated electronically, would make effective ways of communicating with the general public.

vi) A consultative process for setting surveillance priorities and keeping them current

The participants recommended that the current Advisory Committee for Women's Health Surveillance be maintained by LCDC to insert flexibility, dynamism and innovation into the system for surveillance of women's health. The most important task of this group would be to provide advice to LCDC on setting priorities for surveillance: what the criteria should be for setting priorities; which health issues should be added to the list of those under surveillance; which should be removed.

The Advisory Committee should be composed of a diverse group of people from across Canada (including researchers, policy makers, health care providers), nominated for 2-3 year terms, with a portion of the membership rotating annually. It should review trends affecting women's health, follow up and monitor LCDC "red flags" (rapidly increasing problems), develop a consultation strategy for gathering best practices in Canada and abroad, oversee subcommittees focused on health issues of particular importance, identify priorities for research and develop open channels of communication with the users of surveillance information.

Research needs should be communicated by the Advisory Committee to funding agencies. The possibility of issuing Requests for Proposals (RFPs) and other models should be considered to help fast-track priority research.

The Advisory Committee should be the eyes and ears of LCDC in reaching out to the users of surveillance information across Canada, seeking continuous improvement in the effectiveness of the dialogue and feedback process.

A Bureau of Women's Health Surveillance should also be established within LCDC. It should receive advice from the Advisory Committee, develop a strategic plan for moving the women's health surveillance system in the direction already outlined, pursue research on methodologies for surveillance, maintain links within Canada and abroad with the women's health surveillance community to stay on the leading edge of innovation, and work closely with colleagues in other government departments to ensure that policies affecting women's health are made in full knowledge of the best available information.

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V. Presentations

i. Determinants of Women's Health

by Dr. May Cohen

(Speaking notes for a presentation at the opening plenary session of the workshop)

What I have to say today may not present a new concept to many of you, but it is important that if we are to carry out women's health surveillance we must agree on an understanding and comprehensive definition of women's health. Also essential is an understanding of the many factors influencing women's health and well-being as well as a recognition of the barriers to women's achievement of optimal health.

Definition of Women's Health

The understanding of women's health has evolved significantly over the past half century and especially in the past decade. Earlier teachings about women's health were based on the assumption that woman was dominated by her sexual functions, and that the physiology and pathology of her reproductive system provided the key to understanding her physical, mental and moral peculiarities.

Among many practitioners and policy setters, the area of women's health has retained its traditional focus on reproductive issues, and women's health has continued to be defined primarily in terms of childbearing, menstruation and menopause — all of these, whether normal physiologic processes or pathological conditions, deemed to require medical attention.

More recently and, in particular, in the past two decades, we have seen a major shift in our vision and understanding of women's health. In 1985 the U.S. Public Health Service Task Force defined women's health issues broadly as "diseases or conditions that are unique to, more prevalent or more serious in women, have distinct causes, manifest themselves differently in women or have different outcomes or interventions".[1] However, such a definition tends to focus more on disease than on health.

Currently, women's health is perceived as a continuum that extends throughout the life cycle and that is critically and intimately related to the conditions under which women live. Women's health is seen to depend upon complex interactions between individual biology, health behaviour, and the historical, economic and socio-political context of women's lives. As a result of this evolution of our understanding of women's health, the Ontario Women's Health Interschool Curriculum Committee, drawing heavily on the work done by the Women's Health Office at McMaster University, Hamilton, Ontario, developed the following definition of women's health:

"Women's health involves women's emotional, social, cultural, spiritual and physical well-being and is determined by the social, political and economic context of women's lives as well as by biology. This broad definition recognizes the validity of women's life experiences and women's own beliefs and experiences of health. Every woman should be provided with the opportunity to achieve, sustain and maintain health as defined by that woman herself to her full potential."[2]

This definition was adopted by the Canadian Government and provided the framework for the discussions and recommendations on women and health at the Fourth World Conference on Women (the Beijing Conference), held in September of 1995.

A similar understanding of women's health was published by the Commonwealth Secretariat, in which the scope of women's health was defined as follows: (1) women's health concerns extend over the life cycle and are not limited to reproductive problems; (2) women's health problems include but are not limited to conditions, diseases or disorders that are specific to women, occur more commonly in women, or have differing risk factors or courses in women than in men; and (3) health must be considered in broad terms, both positively as well as negatively. Dimensions of health include the physical, mental, social and spiritual.[3]

Implicit in this understanding of women's health is the critical importance of recognizing that women do not constitute a homogeneous group and that women's diversity with respect to race/ethnic background, age, ability/disability, socio-economic class, education and sexual orientation must be taken into account whenever questions with respect to women's health are addressed.

Broader Determinants of Health

A major development in our understanding of health in general and women's health in particular has been the recognition that health status is influenced not only by biology or, indeed, by health care itself, but to a much larger extent by what have been termed the broader determinants of health. These determinants include education, economic status, housing, environment and discrimination based on culture and ethnic background. Powerlessness — a lack of control over one's destiny — has also been identified as a risk factor for disease, chronic stress and higher morbidity and mortality.

A number of publications have drawn attention to these determinants. The Commonwealth Secretariat report[3] states that (1) women's health is directly affected by a range of socio-cultural, physical and psychological factors; (2) women have gender roles and responsibilities that directly affect their level of access to and control of resources necessary to protect their health, resources that are both external (economic, political, information/education, a safe environment free of violence, and time) as well as internal (self-esteem, initiative); (3) women are diverse in their age, class, race or ethnicity, religion, functional capacity, sexual orientation and social circumstances. These factors may lead to inequities that adversely affect their health.

The Ottawa Charter for Health Promotion[4] identified the fundamental conditions and resources for health as peace, shelter, education, good income, a stable eco-system, sustainable resources, social justice and equity.

The publication *Population Health Promotion*[5] draws attention to the multiple determinants of health, including income and social status, social support networks, education, employment and working conditions, physical environment, biology and genetic endowment, personal health practices and coping skills, and healthy child development. The document goes on to point out that, to improve the health of the population, action must be taken on the full range of health determinants.

The National Forum on Health[6] in its final report focused on the importance of addressing health from the broad perspective of the non-medical determinants of health. The Forum believed that the social and economic determinants of health merited particular attention, and one of its goals was to raise awareness of the far-reaching implications to health of social and economic factors.

What Women See As Their Health Priorities

We must also address what women see as their health priorities. In 1990 a policy document, *Working Together for Women's Health: A Framework for the Development of Policies and Programs*,[7] was developed by a working group of federal/provincial/ territorial representatives. This document identified a number of women's health priorities, which included mental health (incorporating substance abuse, sexuality, body image and self-esteem); violence against women; reproductive health; occupational and environmental health; nutrition and fitness; chronic medical conditions; and disability. The report emphasized the importance of addressing how these health priorities affected groups at special risk, or the "doubly disadvantaged". These groups included women with disabilities, immigrant women and women of colour, Aboriginal women, adolescent and elderly women, and women who were poor, isolated and lived in rural areas.

Several years later, focus groups conducted by the Canadian Advisory Council on the Status of Women[8] agreed with many of these concerns but also stressed the importance of HIV and other sexually transmitted diseases, the increase in heart disease, women's diabetes and obesity. It also focused on the difficulties of lesbian women and of accessing appropriate health care as well as on the impact of new reproductive technologies.

In the Monograph *Women's Health and the Context of Women's Lives*,[9] Walters reports on a 1992 study of Hamilton women. The main problems that they mentioned without prompting were stress, arthritis, being overweight, back problems, migraines or chronic headaches, and high blood pressure. The worries these women reported were road traffic accidents and breast cancer. Walters concluded that when women are given a voice, they identify problems that sometimes have received little validation and have seldom been the focus of discussions of women's health.

Concluding Remark

Speaking on behalf of the Advisory Committee for Women's Health Surveillance, I would like to close by saying that it is our hope today that, in addressing priorities for surveillance of women's health, you consider *all* the factors influencing women's health. Understanding the factors that lead to the prevalence of women's ill health is essential if policy decisions are to be influenced by the findings with the goal of improving women's health overall.

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ii. A Multidimensional Approach to Women's Health

by Dr. Arminée Kazanjian

(Speaking notes for a presentation at the opening plenary session of the workshop)

Conceptualizing women's health in terms that are pertinent to women's lives will provide us with better measures of women's health status. While some strides have been made in recent years, we are still far from explaining what actually produces health for different groups of women.

To date, research efforts have been fragmented along disciplinary traditions, producing results that appear to be partial pictures at best, and misleading at worst.

Most health-related research continues to be within the biomedical tradition, in which the definition of women's health is limited to women's biologic function across the life span. Feminist literature critiquing the medical model also tends to focus on reproductive health.

My intent today is not to provide a critique of the biomedical model or to provide a comprehensive or in-depth discussion of it. I will simply give brief examples of selected dimensions, which I hope will help trigger discussions to identify priorities for women's health surveillance.

Focusing on the individual, clinical practice puts the emphasis on personal responsibility and/or blame for high-risk characteristics and behaviour. Health problems are individual problems. While age and sex are risk factors, gender is not.

Epidemiology is the study of the distribution and determinants of diseases and injuries in human populations, and is concerned with the extent of illness in groups and the factors that affect its distribution. The variables of person, place and time are used for understanding the nature of person-environment fit. Sex, age, marital status and socio-economic status, among others, are used in assessing risk and the protective factors that determine health status in groups of people. Social determinants have been emphasized more recently, but not gender as a social construct.

In addition to the clinical and epidemiologic dimensions, we need to capture the underlying social, psychological, political and economic dynamic of women's health in order to develop a meaningful list of priority issues for surveillance and public health assessment. What we need is a multidimensional approach integrated across the disciplines — a concept I have attempted to capture in my drawing of an irregular polyhedron (see the front cover of this report for a reproduction of the drawing). In doing this, we must begin looking at the interactions among the different influences, we must think beyond measuring, and we must recognize what we do and do not know.

Clinical Research	Epidemiologic Research	Social Studies
biomedical model	natural history of disease	structural & cultural context
reproductive health	population at risk	private interests
the individual is the focus	burden of illness	political forces
	populations are the focus	the interaction of influences

iii. How LCDC Defines Surveillance; and What LCDC Hopes Will Come Out of This Workshop

by Dawn Fowler

(Speaking notes for a presentation at the opening plenary session of the workshop)

On behalf of LCDC, I would like to take this opportunity to welcome everyone to this workshop. In particular, I bring greetings and enthusiastic support for this from Dr. Michael Shannon, Director General of LCDC.

Let me start off by saying how excited I am about this initiative: I think we have the chance to create a system of surveillance of women's health issues that will enhance our understanding of women's health and better enable us to target our public health efforts — this must be a collective effort. Among us today, there is a wealth of knowledge and experience, and as we prepare ourselves for the year 2000 and beyond, we have the chance to be innovative and creative in trying to bring about changes in women's health, so we need to take the challenge that has been presented to us and turn it into a reality. Please consider this your workshop. It is the first step in creating a partnership for women's health surveillance.

I have been asked to speak to you this morning about two things: first, how does LCDC define surveillance in terms of this workshop in particular and women's health in general, and second, what are the expected outcomes of this workshop?

I know that there are several of you in the audience who know a great deal more than I do in terms of surveillance and the methodology of surveillance, so please bear with me as I go through my notes, and I certainly welcome your thoughts and comments.

Before actually starting in on how LCDC defines surveillance I thought I would briefly go over what the mission and mandate of LCDC are in order to provide some context as to why LCDC is involved in this workshop.

Mission

- LCDC will facilitate effective, evidence-based public health interventions on a national basis through surveillance, field investigations, applied research and timely dissemination of information related to needs, priorities and strategies.

Mandate

LCDC, as Canada's national authority for public health, is accountable for

- conducting or coordinating the risk assessment of diseases and injuries through national and international surveillance, field investigation, and applied research;
- active dissemination of timely public health information and evidence-based options for public health intervention;
- monitoring and evaluating public health interventions; and
- building national capacity for public health interventions through provision of expertise, quality assurance measures, consensus building and partnerships.

Surveillance: what does this mean . . .

Historically, health surveillance was established to prevent and control the spread of infectious diseases. Although infectious disease remains an essential component of health surveillance, more recently surveillance has expanded into public health and includes the monitoring of chronic diseases, the risk factors associated with these diseases, and injuries; the expansion of surveillance activities continues when we look at issues like women's health. While definitions for these differing surveillance activities have varied, they have all basically conveyed the same principles: surveillance involves the continuous collection, classification, interpretation and dissemination of information. The purpose of surveillance is to have an evidence-based foundation for effective health policy, program decisions and targeted interventions. In other words, health surveillance is an ongoing/continuous process of collecting data on selected variables for differing segments of the population, to detect and address existing and emerging health issues of significant importance. So by observing trends in time, place and persons, changes can be observed or anticipated and appropriate action can be taken.

Because the word "surveillance" can often conjure up many different perceptions for people, I have found that it is often helpful to talk about what surveillance is not, in order to really understand this concept – health surveillance. The purpose of public health surveillance is not to trace individuals nor is it to report on individuals. It is, rather, a process whereby data are reported at the aggregate level, on a continuous cycle, in order to detect changes or emerging issues. There are limitations to surveillance, and not all issues are best understood through surveillance, for example, knowledge and attitudes: it is better to find out about these through surveys, and to conduct randomized controlled trials to determine the efficacy of a drug or a treatment. To fully understand any issue it must be remembered that a dynamic and multifaceted approach is best. You need to have information from several sources — no one data collection activity will answer all the questions or really allow a true understanding of the dynamics or “career” of a health issue.

Examples of actions triggered by health surveillance include the following:

- the identification of segments of the population requiring public health interventions
- the recall of hazardous foods or other products
- new or improved guidelines or regulations
- health promotion programs to educate the public on health risks and the steps they can take to reduce them
- informing health professionals of the most current and effective forms of treatment

By providing detailed knowledge at the aggregate level, surveillance helps ensure that our limited health resources are targeted toward interventions that will have the maximum possible impact — where they are most needed.

Surveillance provides measures of the burden of health issues and their causes and outcomes at national, provincial and local or regional levels. These measures include

- the number of persons affected and their outcomes in terms of survival, quality of life, disability and economic costs
- high-risk groups and important trends over time

Health problems are also measured, including

- HIV/AIDS, influenza and imported diseases
- diabetes, cancer, heart disease, stroke, asthma
- birth defects, low birth weight, infant mortality
- childhood injuries

Health surveillance also identifies health needs and priorities of specific segments of the population, such as women and subgroups of women, for example teenagers or women who suffer from mental health problems.

LCDC undertook an environmental scan and as part of that exercise conducted a gaps analysis of its current surveillance activities. It was determined that there was no comprehensive monitoring and reporting on women’s health. This was considered a significant weakness in its surveillance activities.

To address this, LCDC wanted to put a process in place whereby external experts in women’s health would be consulted to start the process of partnership building between the women’s health community and LCDC, so that a women’s health surveillance system would be a real reflection of the advice and input from those most knowledgeable about women’s health. A surveillance system created in isolation without ongoing input from experts like yourselves would not be a very useful or beneficial undertaking.

LCDC's role in this process is, first, to act as a facilitator in terms of bringing people together, seeking their advice and working collaboratively to define the parameters of women's health surveillance. Second, LCDC can be the focal point for data collection and analysis, since it already obtains many of the data sources and is working with institutions like CIHI and Statistics Canada to look at the feasibility of expanding the type of health information that is made available. Third, LCDC has epidemiologists and other analysts who can work with you in interpreting the results of their analyses and together determine their significance, to reach consensus on the priorities in women's health and what should be the specific issues that make up a surveillance system.

An example of a functioning surveillance system

Name: Canadian Coalition on Cancer Surveillance (CCOCS)

Operation: Registry in each province and territory

Collects information on every diagnosed case of cancer reported in each province/territory

Collects information on
- demographics of patients
- type of cancer
- disease identifier
- treatment identifier

Data are sent from each registry to Statistics Canada to link with the national mortality database for the analysis component of the surveillance system:
- to help plan programs
- to predict future burden
- to plan resource allocation

Management: Governing structure, involves input from key stakeholders — over 600 people

Outcome: By acquiring staging data on such a comprehensive scale, it will be possible to assess the effectiveness of screening programs, e.g., mammography, and the best treatment for each stage. Once this information is known it is disseminated.

So this is how LCDC defines surveillance, how women's health was chosen as a priority area for LCDC and why it is involved in this initiative. Now let me turn to what the anticipated outcomes from this workshop are.

I have been a part of several workshops in which we have been asked to prepare a plan of action or a report in order to achieve a goal or objective. I think we can all recall that some workshops have been more successful than others. It is really important that when we finish by tomorrow afternoon we have the plans for an effective and achievable women's health surveillance program. I want to assure you that these plans will be turned into action, that they will not sit on a bookcase gathering dust, that in fact there is much anticipation around this workshop, and many people are very keen to get to work on the next stages. But first we must build a strong foundation for surveillance, which starts with the work of this workshop.

The questions that you will have to answer in the small groups have been formulated in order to guide the discussion and decision-making process and thus help achieve the objectives of the workshop.

The outcomes of the workshop should be as follows:

- We need to produce a plan for women's health surveillance. By this I mean that we need a report that will be based on the work done here by the Advisory Committee, that I can then take back to LCDC and use as a reference manual or, say, as an instruction booklet on how to implement women's health surveillance. In other words, I am asking for you to do the foundation work.
- To implement a women's health surveillance system, we need to have a list of priority issues. This can be any number — 3, 5, 7, 10 or whatever number — but the list has to be manageable, do-able. We do not have the resources to be able to conduct surveillance in all areas, so we need to know what are the priority areas or issues.
- To accompany this list of priorities, we need to know why these are the priority areas. As there are many competing interests and issues it is important to be able to say why issue X is a priority for surveillance but at this time issue Y is not. This is a critical piece of information for surveillance that is often missing. We need to be able to say why we are doing surveillance of some things and not others. This is also in keeping with the spirit of answering the questions of what did we know, when did we know it and what did we do about it, which addresses the need for accountability and responsibility, and providing information for action.
- Closely connected to this is to know how surveillance of each identified priority area will bring about improvements in women's health. This has to be well articulated so that we know why surveillance needs to be done and what the specific objectives are of conducting surveillance — in other words, what do we hope to achieve by conducting surveillance of a particular issue. We will push you here, in particular, to be very specific.
- After developing a list of priority issues and the reason for these priorities, the next thing to do is to profile or identify which group or groups among women are

most affected by the health issue. This level of detail — of targeting surveillance and treating women as a heterogenous group — is quite critical. For example, if cardiovascular disease is considered an important issue, it is equally as important to try and identify for which segments among women this really is an issue.

- Finally, the last two things that we need to accomplish is to determine how to ensure that LCDC is responsive to changing priorities in women's health and how to evaluate the surveillance activities. For surveillance of women's health issues to be successful there needs to be a systematic process of consultation with you, and so I am asking you to make recommendations on how best to achieve this.
- So, to go back to the question of what is the expected outcome of this workshop, it is to have a blueprint of what should be the components of a women's health surveillance system, why the components have been selected and how to remain responsive to changing issues and needs over time. At a subsequent workshop, we will investigate the how – looking at issues, for example, like data sources, data quality, data availability, data comprehensiveness and the analyses of the data. So with the information from this workshop we will know, with the input from those most knowledgeable about women's health in the country, what should be done in terms of surveillance for women's health. Once we have this, then we can turn to the next stage, which will be the actual implementation of the surveillance system.

Concluding Remarks

In closing, I just want to say that in this room we have a highly motivated, highly experienced and highly educated group of people whose prime interest is women's health. We are all here because we want to make a difference in the lives of women, and while we may have differing opinions of women's health or how to achieve improvements in women's health, we all want to bring about the best possible outcomes for women. We just have to remember that when we get stuck on process or some other issue, we centre back on the reason why we are here — women, women's health and how to improve the state of women's health — for all women living in Canada. As long as we keep that as our ideal, I think we will do just fine, and when the workshop is over we can leave knowing that we really have gone a long way in laying the foundation for achieving our objective — improved women's health.

VI. List of Workshop Participants

Farah Ahmad
The Toronto Hospital
Women's Health Program

Joan Anderson
Professor, School of Nursing
University of British Columbia

Heather M. Arthur
Associate Professor, School of Nursing
Health Sciences Centre
McMaster University

Bronwyn Barrett
Positive Women Network
Vancouver, BC

Judy Bartlett
Winnipeg, Manitoba

B. Lynn Beattie
Division of Geriatric Medicine
Faculty of Medicine
Vancouver Hospital and Health Sciences Centre

Cecilia M. Benoit
Department of Sociology
University of Victoria

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

Allison Brewer
Fredericton, New Brunswick

Jocelyne Bruyère
Cree Nation Tribal Health Centre
The Pas, Manitoba

Nadine Caplette
Aboriginal Health Division
BC Ministry of Health

Elaine Carty
Professor, School of Nursing
University of British Columbia

Angela Cheung
The Toronto Hospital
Women's Health Program
University of Toronto

Ann Clarke
Department of Epidemiology
Montreal General Hospital

Maria De Koninck
Département de médecine sociale et préventive
Université Laval

Sheila Dunn
Assistant Professor
Women's College Hospital
Family and Community Medicine
University of Toronto

Robin Edwards
Hamilton, Ontario

Judith Erola
Whitefish, Ontario

Marsha Forrest
Queen Charlotte Island General Hospital

Lorraine Greaves
Executive Director
B.C. Centre of Excellence for Women and Health

Louise Hanvey
Chelsea, Quebec

Betty Havens
Professor, Community Health Sciences
University of Manitoba

Pat Israel
Toronto, Ontario

Elaine Jolly
Associate Professor
University of Ottawa

Audrey Leader
Health Advisor
Assembly of Manitoba Chiefs

Yvonne Lefebvre
Vice-Dean, Faculty of Medicine
University of Ottawa

Barbara Lent
Victoria Family Medical Centre
University of Western Ontario

Raine MacKay
Vancouver, BC

Verna Mai
Director, Screening Programs
Cancer Care Ontario

Rose-Marie Mayetela
Directrice
Alliance des communautés culturelles
pour l'égalité dans la santé et les services
sociaux (accès)
Montréal, Québec

Joan McComas
Director, Programme of Physiotherapy
University of Ottawa

Karen Messing
Professeure, Département des sciences
biologiques
Centre d'étude des interactions
biologiques entre la santé et
l'environnement (CINBIOSE)
Université du Québec à Montréal

Vaska Micevski
Nurse Practitioner/Cardiac Program
The Toronto Hospital
Women's Health Program
University of Toronto

Betsy Miller
Pharmacia - Upjohn

Michael Monture
Aboriginal Health Access Centre
Hamilton, Ontario

Annette O'Connor
School of Nursing
University of Ottawa

Patricia Petryshen
Vice-President and Chief Nursing Officer
St. Michael's Hospital
Toronto, Ontario

Laura Purdy
Joint Centre for Bioethics
University of Toronto

Gail Erlick Robinson
Director
Women's Mental Health Programme
The Toronto Hospital
University of Toronto

Anne Rochon Ford
Toronto, Ontario

Miroslava Romach
Women's College Hospital
Toronto, Ontario

Charmaine Roye
Avenue Medical Clinic
Brantford, Ontario

Nancy Shosenberg
Oshawa, Ontario

Caroline L. Tait
Aboriginal Women of Montréal, Inc.

(Billie) Wilfreda Thurston
Director, Office of Gender and Equity Issues
Associate Professor
Department of Community Health Sciences
Faculty of Medicine
University of Calgary

Konia Trouton
Coordinator, Population Health
Postgraduate Coordinator
Department of Family Medicine
University of Ottawa

Sari Tudiver
Women's Health Clinic
Winnipeg, Manitoba

Anita Unruh
School of Occupational Therapy
Dalhousie University

Gina Wallas
Quatsino Band Office
Port Hardy, British Columbia

Beatrice Watson
Immigrant Women's Association of Manitoba, Inc.

Ruth C. Wilson
Department of Family Medicine
Queens University

APPENDIX B

Report of a
Women's Health Surveillance Workshop
May 28, 1999
Ottawa, Canada

Federal Government Consultations

Introduction

The second workshop on Women's Health Surveillance was held on May 28, 1999, in Ottawa. Twenty-two persons from various federal government departments attended, including representatives from the Status of Women and other Health Canada directorates, consisting mainly of experts on surveillance and many involved in women's health issues. We were pleased that the Honourable Hedy Fry, Minister of the Status of Women, took time to participate in our workshop.

The objective of this workshop was to determine from a federal government perspective the priorities in women's health that should be part of a national surveillance system. The workshop started with presentations by Pat Kaufert on determining women's health, and these were followed by Dianee Ponée on the Women's Health Bureau and Dawn Fowler on women's health surveillance (text follows). The rest of the workshop was designed to provide an exchange of information, with participants sharing their area of responsibility and mandate. Then, each participant was asked what he/she thought were priority areas for women's health surveillance and why.

By Caren Uhlik and Dawn Fowler, Rapporteurs
Bureau of Operations, Planning and Policy
Laboratory Centre for Disease Control
Health Canada

Determining Women's Health

by Dr. Pat Kaufert

When asked to speak this morning in place of Dr. May Cohen, I was uncertain whether I was to talk about the determinants of women's health or gender as a determinant of health. While closely related, the questions they raise are not quite the same. The first asks: "What are the major factors that determine why (and which) women remain healthy (or become sick)?" The focus is on the individual woman and on differences between women. The second question asks: "How do the determinants of health interact with gender in determining the health of Canadians and of women particularly?"

I telephoned Madame Bégin to ask which one of these questions I should address, but she was more concerned that I should focus on health rather than disease in women. Women with whom we consulted — researchers and representatives from community groups — were also very concerned that health rather than disease should be at the centre of this exercise, to make LCDC more "sensitive" to women's health issues.

Health in the women's literature is defined as a state of positive well-being whose dimensions are not only physical but also social, emotional and spiritual. My own inclination is to see these four dimensions as independent but highly interdependent in their impact on each other; and to see health not from an either/or perspective but, rather, as a continuum with positive and negative poles between which we move to and fro, both as individuals and as societies. Why and in what direction we move between these poles is a function of the determinants of health.

As most of you are aware, the phrase "determinants of health" originated with the book *Why are some people healthy and others not?* (Evans et al. 1994). Although its intellectual foundation is much older, I presume that many of you, though not necessarily all, are familiar with the book. The basic idea was that medical care, while often important in saving the life of the individual, makes only a minor contribution to the health of a population. The major determinants of health at the population level are social and economic. They include a relatively equitable distribution of income, broad access to education, a social environment that provides people with a sense of security and control, stable and satisfying employment, and the availability of social support. Various groups, including the federal government, have revised and added new items, including the physical environment, biology and genetic endowment, healthy child development, health services, personal health practices, coping skills and gender.

The book was rightly criticized (I was one of the critics) for ignoring women, but there is nothing inherent in this list that precludes the addition of gender as a determinant of health. I am not using "gender" as a code word for women (although it is sometimes used that way) or for "sex" in the sense of the biologic differences between men and women, although some would include biology as one of the components of gender. There are almost as many definitions as researchers writing on gender. Nancy Krieger defines gender as "a social construct regarding culture-bound definitions, roles and behaviours for, as well relations between, women and men" (Krieger 1966). Another definition describes gender as "women and men's roles and responsibilities" as determined by "how we are perceived and expected to think and act as men and women because of the way in which society is organized". Both these definitions are American and a little bland, leaving out notions of differential access to political and economic resources and allocation of power along gender lines. They also ignore the mutability of gender. Ideas about what are appropriate gender roles vary widely from society to society, and they change over time within a given society. This may be about to change.

To illustrate the interaction between gender and the determinants of health, I decided to look through the LCDC list of databases and see what I could use as an example. I wanted to ground my remarks in the main purpose of this day, which is to discuss how LCDC might introduce a more "gendered" perspective into its surveillance of the health of Canadians.

I had to assume that LCDC had the ability to break down most of the data in its various data banks by age and sex. However, while I encourage LCDC to run all its data by age and sex as a matter of course, I also question how much such an exercise would advance an understanding of the interaction between gender and the determinants of health. But could be very little indication that this type of data is collected.

Part of the problem is that LCDC was created to monitor disease, but each disease in isolation and only some diseases — i.e., those that kill large numbers of Canadians (cardiovascular disease, cancer, diabetes) or pose potential risk of killing because they are infectious, either directly from person to person (TB, AIDS) or indirectly (through the blood supply or through other media such as food).

This is not a system approach that makes it easy to obey Madame Bégin's admonition to focus on health. If you think back to the definition of health as four dimensions on a continuum, LCDC charts what happens at the negative pole of physical health but without being able to tell us how people got there, i.e., what were the determinants of health and why there are differences by gender.

Interestingly, LCDC is collecting information on diseases that are sensitive to changes in the determinants of health, particularly income and gender. Mortality due to cancer, heart disease, AIDS and TB is higher at lower levels of the income gradient and among men. Possibly, income has its own effect, but is it also an indirect indicator of an environment low in educational level, access to satisfying work, availability of social support and a strong sense of social cohesion? That is one question, but then there is a second, to do with the anomaly of gender: What is it about the way in which roles and responsibilities are created in Canadian society that appears to protect women?

Possibly what we need from LCDC is not a set of separate maps, one for cancer, one for heart disease, one for AIDS, but, rather, a series of overlays that could show how diseases cluster. Work has been done in the U.K., for example, clustering mortality rates by areas of low and high income. Through integration with other statistics — education, occupational characteristics, number of single parents, crime statistics, physical environment, gender environment — a mapping of the country could be created that links determinants of health with position on the average continuum of health/non-health.

What about women?

There I think we must ask ourselves whether Madame Bégin and other women with whom there has been consultation are not right, and that charting health by charting fatal outcomes of a few select diseases gives us only a faint shadow — and at a very late point on the continuum of health non-health.

Looking at gender roles in relation to occupation and health, deaths directly and ambiguously attributable to occupation and occupation alone are relatively few — obviously industrial accidents and a few very distinct diseases, mainly cancers and various respiratory conditions. The information is mainly from men, because these are the groups on which statistics and research have been done. We know relatively little about the impact on women of exposure to various toxins in the work place because it is not studied but also because it is not easy to directly and unambiguously link toxins to work exposure. Another aspect of gender, however, is that the dangerous but often higher paying jobs towards the bottom end of the occupational ladder are largely restricted to men. Women are confined to lower paid, less satisfying jobs over which they have less control — their advantage is that there is less danger to physical survival.

I have brought very few overheads, but thought I would just show this one as it reveals that once one controls for costs associated with sex-specific conditions and final year of life, there is relatively little difference in health as measured by health service use.

Figure 1. Sex Ratios for Per Capita Health Care Expenditures in Manitoba, 1994-1995

Solid circles represent per capita use for all conditions, and open circles represent per capita use for all conditions except sex-specific conditions and treatment in the last year of life. A value of 1.0 represents equivalence between the sexes.

Women's Health Surveillance

by Dawn Fowler

From an analysis of existing surveillance activities within LCDC and of where information is required to address gaps, women's health became identified as an area needing more focused attention in terms of surveillance. At present, we are unable to provide baseline information for monitoring the status of women's health. What we have heard so far is the need for a more comprehensive and coordinated approach to surveillance and analysis in the area of women's health. Thus, we are embarking on this process of consultation, seeking advice from the many experts and those most knowledgeable about women's health to help develop a surveillance system that will contribute to providing the necessary information for public health action and to bring about improved health for women in Canada.

It must be understood that while a very broad data information system on women's health is supported (i.e., surveys, case control studies, observational studies, clinical chart reviews, etc.) and content areas (i.e., chronic conditions, acute conditions, housing, economic situation, violence, poverty, occupation, substance abuse, etc.), here we are talking of just one component, surveillance, so we can monitor trends over time. It is the analyses of these trends that serve as the basis often for developing research questions. It is very easy to become enthusiastic about women's health, to identify deficiencies in the system and try to correct for these. Thus, when proposing issues for surveillance we must make sure we identify ones for immediate implementation and others that will take longer to achieve or require a different collection methodology, as we try to reorient the system of data collection and analysis. Reorienting the system of data collection refers to incorporating issues that traditionally have not been the subject of surveillance. This by no mean suggests that things that have not been part of surveillance in the past cannot be recommended here. I am saying, rather, that we need to understand what surveillance is and its limitations, and decide what is best done through surveillance and what is best done through other means. So we must recognize and note that some issues are better understood through studies rather than surveillance. In other words, no one method of data collection can answer all our research and information needs: surveillance activities should be seen as one data collection activity, and there needs to be a whole complement of data collection activities to fully understand any issue. The purpose of these consultations is to determine what are the priority areas for women's health surveillance.

So what do we mean by surveillance? Surveillance is ongoing data collection, analysis, interpretation and reporting of information for public health action and policy development on a timely basis. The data may come from a variety of sources, but a critical element is that data collection has to be continuous. It is important to distinguish between surveillance and research. Research is directed at answering specific questions, starting with a hypothesis and then undertaking a systematic design to answer the question.

What are the priorities for women's health? That is our work for today and next week when we will be meeting with data suppliers and analytic experts. To help guide today's discussion, then, we need to examine what the priorities are for women's health. We should not limit ourselves by considering what data are available but, rather, discuss what are the issues for women's health surveillance and what the priorities should be. When we meet with the data suppliers we can discuss what is feasible in the short term and what will take longer to achieve, so this is your chance to really discuss what are priority issues and not to feel restricted by what data are currently available. Therefore, we should focus our discussion on what needs to be part of a national surveillance system and how to identify gaps. This does not mean we need to come up with creating a new system of data collection, for example, a new clinical record or vital registration form but, rather, build, enhance or modify existing data collection activities and only introduce new data collection forms or strategies where none exist and bring all these sources together so they can be analyzed and reported on in a timely manner. For example, with regard to abortion, currently there is data collection in terms of number of abortions performed and very limited demographic information. The data for the reports produced by Statistics Canada are collected from hospitals and only a few clinics (even less demographic information is reported by the clinics). At first consultation, it was recommended that surveillance should be expanded, so rather than coming up with new forms or additional forms, work should be undertaken with the various partners to find a way to modify the current method of collecting data; in fact, this process has already begun.

Surveillance is intended to serve public health, health policy and program development. The purpose of surveillance is to monitor and report to those who can act on the information. We face many challenges in trying to establish a national system, and it is extremely important to reflect the heterogeneity of women who live in Canada. Women's health is more than disease, and involves many other aspects, such as environment, housing and economic stability. As well, the diversity of women (ethnicity, health status, economic situation, language, literacy, education, etc.) must be honoured and recognized. For example, women of different cultures and ethnic backgrounds report on things differently; thus we need to have a system that respects this, one that includes asking meaningful questions and allows for different methodologies to be employed for data gathering activities. It is important to consider using non-government organizations and community organizations to collect data. Qualitative research is scientific. However, it is often not accepted by many, and this has to change. We have to be accepting and supportive of different methodologies and questions if we are truly interested in understanding women's health and trying to bring about improvements.

We heard in the first workshop that quality of life is an important aspect in relation to women's health. Surveillance data have been lacking in several areas, and quality of life is one such area. Quality of life is composed of several issues, such as poverty. There are many factors associated with poverty — violence, depression, discrimination — and these all contribute to a poorer quality of life for women. Another issue has to do with pain — why is it that women suffer from pain? Pain often contributes to mental health and thus quality of life issues. Discrimination is another example of an issue that contributes to quality of life.

How do we measure these and other issues that do not fall within the domain of conventional surveillance activities? The problem is that in many of these areas it is often difficult or almost impossible to find the population most affected. But if there is a real desire to understand the populations most affected by these issues, then approaches can be developed. One example comes from Australia. The Australian Health Survey has two instruments: a classic epidemiologic model to look at women's health in the general population and a different instrument and approach for Aboriginal, Vietnamese and poor women.

For a surveillance system that is proposed here to be successful, there has to be interdepartmental cooperation. Such cooperation, for example, will help fill gaps by allowing linkage of databases and will thus facilitate analysis. For example, HRDC may have data on social aspects and Industry Canada has data on economic and work aspects, and the information can be merged.

In our discussion today, we should not be constrained by what is currently being collected. We do have to be concerned with and ensure the quality of data, and realize that not everything can be done. The challenge for the Advisory Committee is conceptually to go beyond conventional surveillance frameworks and think about how to bring forward recommendations for change. How do we make a difference? In order to recognize the fact that Canada is made up of different populations, each government department needs to think this way, e.g., link unemployment data with data on depression, suicide and health status. Linking of departments and partnership building has to occur in order for these improvements to be made.

Priorities identified

Group discussion

Workshop participants were asked: What are the priority areas in women's health?

How are they important? What subgroups/dimensions of women's lives should be the focus? The following is a summary of the group discussion that ensued.

As the group discussed various priorities, many of the same issues were identified by most of the participants. They were violence, abortion, quality of life, substance use, mental health, paid and unpaid work and, even though it is not a health issue, it was noted that gender-based analysis must be implemented when women's health is analyzed. Compared with the first workshop, where there was the listing of both disease-specific priority areas and issues not necessarily considered health issues (such as working conditions and housing) the group in the second workshop focused more on non-disease specific issues such as violence and working conditions.

Violence was identified as a priority area. It was noted that data collection is not routine, and there is an enormous lack of national level information. It was stated that all types of violence — domestic violence, violence against women and family violence — are often linked to socio-economic status, substance abuse and poverty; in addition, many situations of power imbalances lead to violence. However, it is important to realize that violence crosses all socio-economic levels. Traditionally, violence has come under the jurisdiction of the justice system, and both the issue and the individuals have had to work through that system. It is now being recommended that violence be seen in a broader context and be considered as a health issue as well, and that the various areas of the mandate be incorporated rather than working in isolation. In other words, violence should also be part of the health agenda.

The group talked about implementing a street youth surveillance system in which there would be contact with health services other than family services or social welfare alone. The system should include questions about psycho-social determinants and health conditions.

Recommendations put forward by workshop participants for violence surveillance included the following:

- Make it mandatory for police to report all violence and causes; create a national standard for defining and reporting on violence.
- Follow the example of emergency departments in U.S. hospitals, which must follow specific criteria to screen for all violence in order to obtain hospital accreditation.
- Ensure interdisciplinary linkages are in place — Justice Canada, Statistics Canada and Health Canada at the national level — and encourage the same type of interdisciplinary links at the provincial and regional levels.
- Address violence in relationships: surveillance needs to address many aspects — type of violence, place of occurrence and perpetrator; conducting another Violence Against Women survey was encouraged.
- Addressing violence in rural and urban women. Social differentiation in Canada, usually examined by regions (West, Mid, East, North), should be analyzed by more meaningful breakdowns — not by province but, rather, by large metro areas, fringes, rural regions, etc. — as this would be more helpful than remaining with traditional analysis.

Mental health has not been the subject of large-scale national level surveillance in the past, and it was recommended by the group that mental health be part of a women's health surveillance system. It was stated that mental health crosscuts many issues, e.g., violence, stress, depression, anxiety and eating disorders. It is also necessary to take a life cycle approach to mental health in women, young children and their activities, adolescents' sexual health, young women's work satisfaction, young mothers, women of menopausal age and the aging population. To fully understand mental health and its impact on women there must be a move away from viewing it merely as a women's issue and seeing it in a broader context in which the impact of other events or the social/economic climate has an effect. For example, during the development of the new Employment Insurance Program it was noted that many women worked part-time or worked at two part-time jobs and thus never qualified for unemployment insurance. Changes were implemented whereby eligibility was determined by the number of hours worked as opposed to the number of weeks worked throughout the year. The outcome of this change was dramatic — 600,000 more women were then eligible to collect benefits.

Abortion was seen to be a very important issue for improved surveillance. Data on the incidence of abortion exists; however, there is a lack of data on time to procedure, distance traveled to obtain services, and the abuse that some endure to obtain an abortion. The stereotype has been that young women generally have abortions. It was felt important to try and understand who is having abortions and why, and to monitor the impact of genetic testing. The group also noted that it would be important to have information on later stage abortions and later age abortions.

Quality of life was identified as an important determinant/factor in women's health. Work must be undertaken to define what is meant by quality of life and its relationship to women's health. However, it was also noted that examining quality of life will require a different concept of data collection and surveillance. Some topics discussed that would come under quality of life were depression, unhappy relationships, stress, unpaid/paid work, and discrimination, e.g., how immigrant women are treated differently, how issues of language can be a major factor in accessing available services and resources, poverty, and sexual exploitation.

Substance use in women was stated to be an important issue and should be the subject of surveillance. The use of illegal substances, prescription and non-prescription, self-medication and intravenous drug use are of serious concern, are costly and have devastating effects on the woman and her family, partner and children. More information is needed on addiction, particularly among marginalized groups, e.g., sex trade workers, difficult to reach groups (street youth), Aboriginal women, and those using alcohol while pregnant (fetal alcohol syndrome). The development of a well-designed study and an outreach program is important so that information on various issues can be obtained at one time from these women.

Smoking and smoking initiation among women, particularly young women aged 12-18 years, was raised as an important issue for continued surveillance. While it was mentioned that Health Canada is conducting surveillance of tobacco use in Canada, two limitations were noted, and corrections were called for: first, that the age for surveillance be lowered from age 15 to age 12, and, second, that the surveillance of tobacco use be designed to include the Territories. Tobacco use is a common factor and contributor to the leading causes of morbidity and mortality among women in Canada. Thus it is important to have timely and ongoing data.

Economics and poverty are related to many aspects of women's health. The group recommended that work be undertaken to define poverty in a way that would permit its inclusion into surveillance systems.

Environmental and occupational health. The group also wanted to see surveillance undertaken on environmental and occupational health issues and how they affect women's lives, in particular injuries and illnesses sustained by women.

Occupational health and safety. Some data are available and are collected by provinces, but only on reported cases. This issue was also seen as important by the group.

Work life of women. Paid and unpaid work affects all women regardless of background and contributes to mental health and stress (young women workers, pressures, income levels, stress factors). While there is some information in various databases, it was recommended by the group that a review of all relevant databases be examined to determine which data elements are within each and whether there is a way the databases could be linked.

Isolation stress can occur at any age or within any living arrangement and can be in either a rural or an urban setting. Isolation was identified as another issue difficult to define and measure, and has not been a part of surveillance in the past, but is a critical factor for women. What type of network do women have, do they know how to access resources and services, do they have support — these are things that were identified as requiring information.

Muskulo-skeletal conditions, including osteoporosis and arthritis, require ongoing surveillance.

Aboriginal and Inuit were identified as groups often marginalized, living in poverty, isolated, suffering from many chronic conditions and not usually part of any surveillance activity. It was recommended that an effort be undertaken to know more about these groups and how best to provide programs and services to meet their needs.

Menopausal issues and screening were identified for surveillance. In particular, attention should be focused on the introduction of new therapies and treatments and their impacts. In terms of screening, surveillance should focus on areas such as access, communication about when screening is appropriate and for what, and creation of questions that are meaningful to women.

Gender-based analysis. The group stated that if Health Canada is really interested in women's health, then GBA has to be undertaken. It is no longer good enough to do breakdowns according to sex: GBA must be done in order to fully understand women's health and how it is affected by various conditions and social circumstances. GBA has been promoted by the Status of Women Canada (SWC) and is endorsed by Health Canada. It should be implemented at the beginning of a project, not the end. Women's health is overall better served through a gender-based lens.

GBA was identified as a priority for women's health surveillance. LCDC needs to do a better job of applying the concept of gender and gender-based analysis to its work. Many experts on GBA at Status of Women Canada can be loaned to other departments to specifically implement GBA within a department. The first step is initial development, when trained people are needed to help develop GBA. GBA should be neutral and look at the impact for both men and women rather than for women only. It was suggested that LCDC have a visiting scholar in residence for a specified period of time to orient staff on how to conduct GBA.

List of Workshop Participants

Jill Austin
Chief Executive Officer
Canadian Centre on Substance Abuse

Adelaida Bawagan
Research Analyst
Policy, Planning and Coordination
Health Protection Branch
Health Canada

Leslie Forrester
Research Analyst
Medical Services Branch
First Nations Inuit
Health Programs Analysis Division

The Honourable Hedy Fry
Minister
Secretary of State
(Multiculturalism)(Status of Women)

Anne Gravereaux
Manager, Health and Safety
Products and Services
Canadian Centre for Occupational Health
and Safety

Nora Hammell
Research Analyst
Research Directorate
Status of Women Canada

Susan Hasnain
Associate Director
Bureau of Policy Coordination
Therapeutic Products Programme
Health Protection Branch
Health Canada

Katalin Kennedy
Expert-Women Issues
Family Violence Prevention
Health Promotion and Programs Branch
Health Canada

Catherine McCourt
Director
Bureau of Reproductive and Child Health
Laboratory Centre for Disease Control
Health Canada

Christina Mills
A/Director
Cancer Bureau
Laboratory Centre for Disease Control
Health Canada

Brian Pearl
Policy Analyst
Health Policy and Information
Directorate
Health Canada

Diane Ponée
Director
Women’s Health Bureau
Health Canada

Nancy Jean Waugh
A/Director General
Policy Analysis and Development and
External Relations Directorate
Status of Women Canada

Tom Wong
Chief, Division of STD Prevention and
Control
Bureau of HIV, AIDS, STD and TB
Health Canada

APPENDIX C

Report of a Women's Health Surveillance Workshop
June 3, 1999
Ottawa, Canada

Data Suppliers, Database Managers and Analysts

The third and final women's health workshop on surveillance was held on Thursday, June 3, 1999. Experts in surveillance and data analysis, and database managers from various government and non-governmental organizations, universities and research institutes were invited to attend. The purpose of this workshop was to identify what sources of information are available according to the priorities identified in the first two workshops; discuss the quality of the available data; and decide how to go about collecting data for the identified gaps and how to link various databases.

The workshop started off with a presentation by May Cohen on the determinants of health, followed by Dawn Fowler speaking on women's health surveillance. This was followed by Arminée Kazanjian giving a presentation on women's health surveillance and gender-based analysis, and the presentations concluded with Pat Kaufert giving examples of women's health issues and how to conduct gender-based analysis. After the presentations the group discussed the availability of data and their quality in terms of the priorities raised in the first two workshops.

By Caren Uhlik and Dawn Fowler, Rapporteurs
Bureau of Operations, Planning and Policy
Laboratory Centre for Disease Control
Health Canada

The Determinants of Women's Health

by Dr. May Cohen

What I have to say today may not present a new concept to many of you, but it is important that if we perform women's health surveillance we must agree on an understanding and comprehensive definition of women's health. Also essential is an understanding of the many factors influencing women's health and well-being as well as a recognition of the barriers to women's achievement of optimal health.

Definition of Women's Health

The understanding of women's health has evolved significantly over the past half century and especially in the past decade. Earlier teachings about women's health were based on the assumption that woman was dominated by her sexual functions, and that the physiology and pathology of her reproductive system provided the key to understanding her physical, mental and moral peculiarities.

Among many practitioners and policy setters, the area of women's health has retained its traditional focus on reproductive issues, and women's health has continued to be defined primarily in terms of childbearing, menstruation and menopause — all of these, whether normal physiologic processes or pathological conditions, deemed to require medical attention.

More recently and, in particular, in the past two decades, we have seen a major shift in our vision and understanding of women's health. In 1985 the U.S. Public Health Service Task Force defined women's health issues broadly as "diseases or conditions that are unique to, more prevalent or more serious in women, have distinct causes, manifest themselves differently in women or have different outcomes or interventions".[1] However, such a definition tends to focus more on disease than on health.

Currently, women's health is perceived as a continuum that extends throughout the life cycle and that is critically and intimately related to the conditions under which women live. Women's health is seen to depend upon complex interactions between individual biology, health behaviour, and the historical, economic and socio-political context of women's lives. As a result of this evolution in our understanding of women's health, the Ontario Women's Health Interschool Curriculum Committee, drawing heavily on the work done by the Women's Health Office at McMaster University, Hamilton, Ontario, developed the following definition of women's health:

> *"Women's health involves women's emotional, social, cultural, spiritual and physical well-being and is determined by the social, political and economic context of women's lives as well as by biology. This broad definition recognizes the validity of women's life experiences and women's own beliefs and experiences of health. Every woman*

> *should be provided with the opportunity to achieve, sustain and maintain health as defined by that woman herself to her full potential."*[2]

This definition was adopted by the Canadian Government and provided the framework for the discussions and recommendations on women and health at the Fourth World Conference on Women (the Beijing Conference), held in September of 1995.

A similar understanding of women's health was published by the Commonwealth Secretariat, in which the scope of women's health was defined as follows: (1) women's health concerns extend over the life cycle and are not limited to reproductive problems; (2) women's health problems include but are not limited to conditions, diseases or disorders that are specific to women, occur more commonly in women, or have differing risk factors or courses in women than in men; and (3) health must be considered in broad terms, both positively as well as negatively. Dimensions of health include the physical, mental, social and spiritual.[3]

Implicit in this understanding of women's health is the critical importance of recognizing that women do not constitute a homogeneous group and that women's diversity with respect to race/ethnic background, age, ability/disability, socio-economic class, education and sexual orientation must be taken into account whenever questions with respect to women's health are addressed.

Broader Determinants of Health

A major development in our understanding of health in general and women's health in particular has been the recognition that health status is influenced not only by biology or, indeed, by health care itself, but to a much larger extent by what have been termed the broader determinants of health. These determinants include education, economic status, housing, environment and discrimination based on culture and ethnic background. Powerlessness — a lack of control over one's destiny — has also been identified as a risk factor for disease, chronic stress and higher morbidity and mortality.

A number of publications have drawn attention to these determinants. The Commonwealth Secretariat report[3] states that (1) women's health is directly affected by a range of socio-cultural, physical and psychological factors; (2) women have gender roles and responsibilities that directly affect their level of access to and control of resources necessary to protect their health, resources that are both external (economic, political, information/education, a safe environment free of violence, and time) as well as internal (self-esteem, initiative); (3) women are diverse in their age, class, race or ethnicity, religion, functional capacity, sexual orientation and social circumstances. These factors may lead to inequities that adversely affect their health.

The *Ottawa Charter for Health Promotion*[4] identified the fundamental conditions and resources for health as peace, shelter, education, good income, a stable eco-system, sustainable resources, social justice and equity.

The publication P*opulation Health Promotion*[5] draws attention to the multiple determinants of health, including income and social status, social support networks, education, employment and working conditions, physical environment, biology and genetic endowment, personal health practices and coping skills, and healthy child development. The document goes on to point out that, to improve the health of the population, action must be taken on the full range of health determinants.

The National Forum on Health[6] in its final report focused on the importance of addressing health from the broad perspective of the non-medical determinants of health. The Forum believed that the social and economic determinants of health merited particular attention, and one of its goals was to raise awareness of the far-reaching implications to health of social and economic factors.

As well, Health Canada has developed its list of determinants of health.[7] Many of the determinants of health are interrelated, and one of our challenges is to get clearer data on them. These include the following:

> Income and social status: This is the single most important determinant of health. Many studies show that health status improves at each step up the income and social hierarchy. As well, societies that are reasonably prosperous and have an equitable distribution of wealth have the healthiest populations, regardless of the amount they spend on health care.
>
> Social support networks: Support from families, friends and communities is associated with better health. Some experts conclude that the health effect of social relationships may be as important as established risk factors such as smoking, physical activity, obesity and high blood pressure.
>
> Education: Health status improves with level of education, including self-ratings of positive health or indicators of poor health, such as activity limitation or lost work days. Education increases opportunities for income and job security, and equips people with a sense of control over life circumstances — key factors that influence health.
>
> Employment and working conditions: Those with more control over their work circumstances and fewer stress related demands of the job are healthier. Work place hazards and injuries are significant causes of health problems. Unemployment is associated with poorer health.
>
> Physical environments: Physical factors in the natural environment such as air, water and soil quality are key influences on health. Factors in the human-

built environment such as housing, workplace safety, community and road design are also important influences.

Biology and genetic endowment: The genetic endowment of the individual, the functioning of various body systems, and the processes of development and aging are a fundamental determinant of health. Biological differences in sex and socially constructed gender influence health on an individual and population basis.

Personal health practices and coping skills: Social environments that enable and support healthy choices and lifestyles, as well as people's knowledge, intentions, behaviours and coping skills for dealing with life in healthy ways, are key influences on health.

Healthy child development: The effect of prenatal and early childhood experiences on subsequent health, well-being, coping skills and competence is very powerful. For example, a low weight at birth is linked with health and social problems throughout the life span. Mothers at each step up the income scale have babies with higher birth weights, on average, than those on the step below.

Health services: Health services, particularly those designed to maintain and promote health and prevent disease, contribute to population health.

What Women See As Their Health Priorities

We must also address what women see as their health priorities. In 1990 a policy document, *Working Together for Women's Health: A Framework for the Development of Policies and Programs*,[8] was developed by a working group of federal/provincial/ territorial representatives. This document identified a number of women's health priorities, which included mental health (incorporating substance abuse, sexuality, body image and self-esteem); violence against women; reproductive health; occupational and environmental health; nutrition and fitness; chronic medical conditions; and disability. The report emphasized the importance of addressing how these health priorities affected groups at special risk, or the "doubly disadvantaged". These groups included women with disabilities, immigrant women and women of colour, Aboriginal women, adolescent and elderly women, and women who were poor, isolated and lived in rural areas.

Several years later, focus groups conducted by the Canadian Advisory Council on the Status of Women[9] agreed with many of these concerns but also stressed the importance of HIV and other sexually transmitted diseases, the increase in heart disease, women's diabetes and obesity. It also focused on the difficulties of lesbian women and of accessing appropriate health care as well as on the impact of new reproductive technologies.

In the Monograph *Women's Health in the Context of Women's Lives*,[10] Walters reports on a 1992 study of Hamilton women. The main problems that they mentioned without prompting were stress, arthritis, being overweight, back problems, migraines or chronic headaches, and high blood pressure. The worries these women reported were road traffic accidents and breast cancer. Walters concluded that when women are given a voice, they identify problems that sometimes have received little validation and have seldom been the focus of discussions of women's health.

Concluding Remark

It is our hope today that, in addressing priorities for surveillance of women's health, you consider *all* the factors influencing women's health. Understanding the factors that lead to the prevalence of women's ill health is essential if policy decisions are to be influenced by the findings with the goal of improving women's health overall.

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Women's Health Surveillance

by Dawn Fowler

Since many of you are familiar with surveillance methodologies, the issues surrounding surveillance and data collection, and in view of the very busy day ahead of us, I will keep my comments brief. The reason for this initiative of trying to develop a women's health surveillance system is based on a review of existing surveillance activities and the identification of a gap with regard to women's health. It was noted that several of the bureaux do conduct surveillance on various aspects of women's health; there is, however, no comprehensive and systematic surveillance of women's health. Therefore, LCDC, under the direction of Dr. Michael Shannon, established an Advisory Committee of external experts to undertake consultations in order to determine the priorities in women's health. The purposes of today's workshop are to identify potential data sources for women's health surveillance based on priorities identified in previous workshops; to discuss what is achievable in the short term, mid term and long term; and to consider what work needs to be undertaken to obtain information on issues that are more challenging in terms of data collection. We must keep in mind that no one data source can provide all the data for all issues. We must be willing to recognize that traditional sources of data for surveillance purposes, e.g., clinical charts, vital statistics and hospital records, serve an important function for surveillance, but that other sources of information and more qualitative approaches to data-gathering have to be included; furthermore, in some cases a census may not be necessary, and a sample strategy is sufficient.

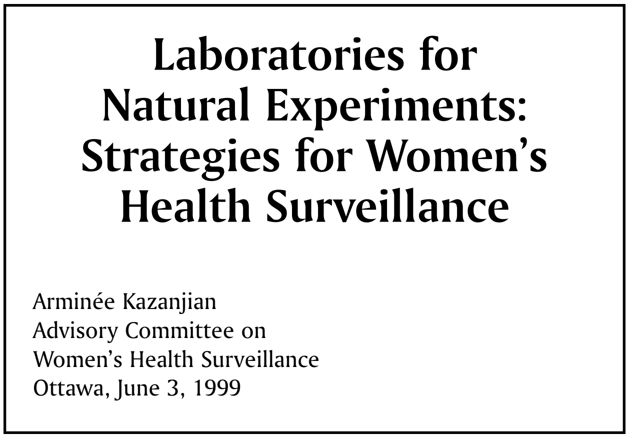
Let me also state that there is a difference between ongoing surveillance (monitoring trends over time) and research (guided by a hypothesis and trying to answer a specific question). The reason that I raise this is not to limit what would be considered topics for surveillance but to distinguish what data needs are required for surveillance purposes. We have to define what we mean by surveillance — it is not the one-off study or the one-time survey — it is ongoing, systematic and routine data collection, analysis, interpretation and reporting. At times in the previous workshops there was difficulty remaining focused on surveillance, and the discussion often went into areas that might be better covered by research. With regard to surveillance systems, usually people think in terms of the traditional sources, e.g., CIHI and Statistics Canada. LCDC uses these sources, but from what we have heard from the experts we need not only to continue with these sources and work with those responsible to help make them better address our information needs, but also to consider different, non-conventional sources of information. We are not necessarily looking to create new forms of data collection or establish a new survey, but, first, to exploit the data that are already being collected, e.g., by better linkages; second, to improve the existing methods and instruments of data collection so that they are more responsive to the information needs; and, third, to develop new tools and/or strategies to address the gaps that cannot be covered by existing sources of data. To facilitate this process, we must be willing to examine how we have been analyzing data and how this can be modified, especially by conducting gender-based analysis to better understand women's health issues. Some of the questions we need to address today are as follows: Which databases need to be modified and how? Do new data collection forms or survey instruments need to be created — if so, for what issues and/or populations? How do we ask questions that are relevant and sensitive to the issues and challenges facing women? Which subgroups do we need to focus on, and how should we do this? What would be an appropriate sample size for marginalized populations? These are all important questions and hopefully they will start off, but by no means limit, our discussion today.

Laboratories for Natural Experiments: Strategies for Women's Health Surveillance

by Arminée Kazanjian

Slide 1

- Large datasets - longitudinal - linked - can provide opportunities for extremely important and complex examination and analysis of health determinants/outcomes, and tracing/tracking of certain events over short or long periods. Augmented by other information.

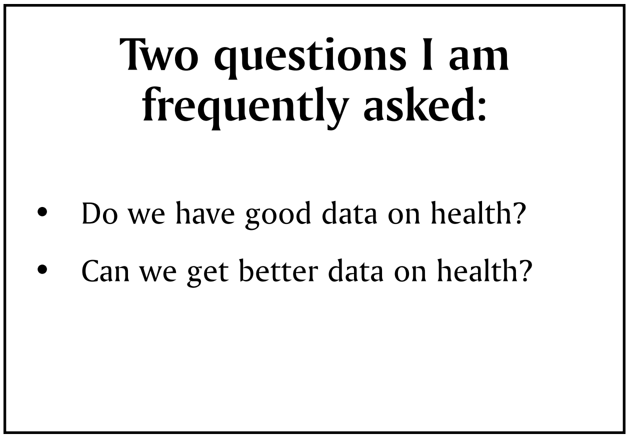


Laboratories for Natural Experiments: Strategies for Women's Health Surveillance

Arminée Kazanjian
Advisory Committee on
Women's Health Surveillance
Ottawa, June 3, 1999

Slide 2

- The first question always makes me a bit nervous: I never know whether it is a trick question — Does the person asking it want to learn more in order to intervene or is the question an excuse for not doing anything (policy, program, or other intervention)?
- Social action will need data to succeed; better data will produce better health intervention.



Two questions I am frequently asked:

- Do we have good data on health?
- Can we get better data on health?

Slide 3

- Do we have good data with which to do women's health surveillance?
- 1st step - framing the research question
- Capturing the dynamic of what actually produces health for different groups of women, for example, osteoporosis in women: CIHI hip replacement registry. Risk factors: bone density, menopause, race — this is what you see in the literature without the GBA. Put different lenses on and look into the "dynamic" — not low BMD age (men 15 years later), not race or socio-economic conditions, not clinical

diagnosis of menopause — cultural norms of how the different phases of the life cycle are regarded (e.g., Japan), falls causing hip fractures, who falls?

Clinical determinants
- taking too many drugs (anti-anxiety)
- poor vision
- smoker/drinker

Social determinants
- lives alone - widow/single senior
- poor dietary habits

Framing of issues through GBA lenses

- capturing the dynamic of what actually produces health of different groups of women
- developing indicators that contribute to understanding the nature of differences between men and women

- The intent here is not a thorough examination, but an overview of the dynamic; therefore, indicators need to be identified that measure accurately the social as well as the clinical determinants, so as to capture the nature of the differences between men and women.

Slide 4

Broadening methodologic preferences

- Qualitative
- Quantitative
- Multi-level observations

- This is more likely to happen if we move beyond the traditional methods of surveillance, especially in instances where we need to gain better understanding of issues in order to then target a subpopulation or one phase of the life cycle for surveillance purposes. Therefore, we can learn more about a specific woman's health concern by mixing methodologies, where qualitative data complement quantitative data. In addition, the unit of observation can be varied: an individual, a family, a community.

  Example: Outcomes project — this takes us to the specifics of databases that I am doing with an international group of researchers, in which surveys of individual nurses are being rolled up to calculate hospital level scores, then used in combination with hospital discharge data, and annual hospital surveys (MIS).

- This takes us to the specifics of databases.

Slide 5

- How to make the most of existing databases? We can increase the utility of existing administrative and survey databases by:

  1) minor technical improvements
     - unique identifiers (scrambled, if you wish)
     - combining person-specific and aggregated data
     - central repository collection of data
     - one agency for entire database
     - harmonized standards
     - coding and reporting

  2) by substantive improvement
     - addressing data gaps
     - this need not be entirely new surveys or registries; in most cases an additional field or two in the existing one
     - surveys or reporting tools would yield high returns
     - information exchange protocol

Optimal development of databases

- technical aspect
- substantive aspect

Slide 6

- In order for any of this to happen a surveillance governance structure and framework is needed to guide/control the various aspects of data sharing and exchange.

Governance and framework

- relationship between programs/data stewards
- data arrangements among data stewards
- rules of access & dissemination

Examples of women's health issues and how to conduct gender-based analysis

by Pat Kaufert

I was asked to develop three examples — mini-case studies — of gender-based analysis that could be introduced into the work of LCDC. In effect, I have chosen one, which is specific to women, one in which the "treatment" is specific to women although the disease affects both men and women, and one in which the rationale is based on differences in the expression of the same disease in women relative to men.

One of the case studies focuses exclusively on a database collected and maintained by LCDC. It is also a database that was of particular interest to women who met at our first workshop and for which they had some very specific recommendations for change in both the data to be collected and in analysis.

The second is an example of a situation in which the database "owned" by LCDC might be used to provide one piece in a puzzle whose complete solution depends on collaboration with other researchers/research institutes (CIHR), and which requires studies ranging from basic laboratory-bench science through to an ethnographic study of women at work.

The third involves a database that, to the best of my knowledge does not exist, although it might, and it might belong to LCDC. I have intended to use it as an example of the way in which a fresh analysis of a database might lead to a collaboration between different bureaux of LCDC, with Statistics Canada and ultimately with the researchers of databases and pharmaco-epidemiologists.

Abortion

The first case study looks at abortion. One of LCDC's responsibilities is the maintenance of the Canadian Perinatal Surveillance System, which includes an abortion database. Information is collected from hospitals and clinics, and includes the following indicators: age, procedure used, gestational age and complications. Information is reported by number of abortions per 1000 women in the age range, number of abortions per 100 live births, frequency of different procedures and number of abortions at various gestational ages.

Discussion of this database by women at the workshop focused on questions of access: on the distance women must travel to obtain an abortion, the length of time that elapses between the decision to have an abortion and the abortion taking place, and any changes in access as a response to pressure. Abortion was also discussed in the context of the impact of the new genetics on women's health. The questions here were not only whether the availability of new tests for "new" genes would increase the number of abortions, but also whether the expansion of prenatal testing to the general population of pregnant women (as in some provinces) will have a major impact not only on the rates/numbers but also on the balance between different types of procedures, the site, the age distribution of the women and the gestational age.

Given that there are always constraints on the ability to ask agencies to provide additional data, coupled in the particular case of abortion with strong ethical constraints, how might this objective be achieved?

My own suggestion — although there are others — would be to collect just two pieces of additional data: the postal code of the woman having the abortion and whether or not the decision to abort was based on the detection of a fetal anomaly. How the anomaly was discovered (genetic test or by routine ultrasound) and the type of anomaly would add valuable additional information.

Collecting postal codes, though not ideal, is the least intrusive method of determining access as a function of geography. It could be used to map the catchment area of the hospital or clinic from which the woman came. The question of access in terms of the delay before a woman has her abortion would be difficult. The availability of postal codes would allow a more detailed mapping of the distribution of abortion across the country, based not on the location of the providers but of the women having abortions. As a bonus, a more interesting analysis might be to attach income data from Statistics Canada to the postal code and then map abortions by income quintile.

Determining what barriers exist in terms of time elapsed between the abortion and the decision is more difficult without direct questioning of the woman herself — ethically questionable and doubtful methodologically. One might be able to use the number of days elapsed between the time a woman was referred (or referred herself) and the date of the abortion. This is not ideal but is the least intrusive.

There are many barriers that may intervene to delay the timing of an abortion, including the timing of testing in a pregnancy and delay before getting the results and making a decision. Analysis of the relationship between gestational age, type of procedure and whether the abortion is the result of the detection of some form of fetal anomaly would provide some insight into this issue, but to understand the impact of delays on women themselves would require quite a different type of study.

The catalyst here is the recommendations of women outside LCDC, the willingness of LCDC to listen and to convince data providers, and an awareness that only LCDC has the type of surveillance that will allow spotting of trends in abortion patterns across the country in response to the new genetics.

Lung Cancer

This example was developed on the basis of a report of a British study, which found that women are more likely than men to develop small cell cancer, a more aggressive form of the disease that is also less responsive to treatment. The investigators proposed an explanation based on the ways in which men and women smoke. Men (the study claims) are more likely to keep a cigarette in their mouths while they work and are therefore less vulnerable than women to "particle deposition and lung cancer". I do not want to discuss whether this particular hypothesis is biologically plausible, but rather to see it as setting up a puzzle to which LCDC may hold one of the pieces.

There is no doubt that lung cancer is a major problem in women's health, and there are other studies suggesting that if women smoke they are more vulnerable than men, but this is the first explanation I have seen that is based on gender differences in behaviour. Either because of the nature of their work or their socialization into gendered patterns of smoking behaviour women develop a different type of lung cancer.

One piece of the puzzle is presumably pure laboratory research, comparing lung samples from male and female smokers to determine if there is a difference in particle deposition. Let us suppose this work is done by an academic researcher in a laboratory who has good contacts in LCDC. She knows that LCDC has a cancer surveillance system database that includes risk information (such as smoking), incidence and survival data. Unsure if it can identify small cell cancers or cancer staging at the time of diagnosis, but presumes it has some capacity to analyze what data they do have looking for differences in the type of cancer by gender and such other things as treatment patterns and survival time. Results are promising and she convinces someone in the Cancer Bureau to do the analysis and convinces LCDC to take a step further.

LCDC might consider paying Statistics Canada to develop a question or two for the next NPHS on whether the respondent smokes while working and whether the cigarette is kept in the mouth while doing so. Alternatively, one might contact the Canadian Cancer Institute to fund a qualitative researcher to conduct a series of interviews on "images" of proper smoking behaviour held by men and women. Alternatively, one might organize this, then couple it with a very precisely designed collection of observational data of men and women — of how they smoke.

None of these pieces — the ethnography, the observational study, the survey, the LCDC cancer surveillance data, the lung tissue — can answer the question posed by the British study, but each offers a piece of new evidence. We need both data and development of a network between people with different methodologic skills.

Alzheimer's Disease

I developed this example to illustrate collaboration within LCDC itself and between LCDC and health services researchers and pharmaco-epidemiologists.

To the best of my knowledge LCDC does not have an Alzheimer database, but let us presume that it does and that it includes both gender and postal codes. A biostatistician/medical geographer working with the database "borrows" the program from the abortion database that maps the Canadian population by income gradient, tries it out on the Alzheimer database and finds that the income gradient and the disease gradient have a very similar slope. She convinces LCDC to let her try the same analysis on coronary heart disease and finds the same pattern. She might see it simply as a confirmation of Bob Evans and the determinants of health model or, if familiar with the women's health literature, she might wonder whether she should develop a proposal to look at the relationship from a treatment perspective — in this case a prophylactic treatment in the form of hormone therapy.

One of the dilemmas facing women at the moment is whether we should believe the promise that estrogen will protect notably heart and mind. The pharmacare databases, at least those capable of linkage with provincial acute hospital care databases, could easily provide an analysis of estrogen use by income gradient, although probably only Saskatchewan's has the depth to explore relationships between estrogen use and subsequent risk of Alzheimer's.

Group discussion

Priorities

Following the first workshop on Women's Health Surveillance a list of specific diseases and other health issues were identified as priorities, and there was a call for examining other issues traditionally not considered as health issues. As well, there was a call for using methodologies that have not usually been used in the collection of data for surveillance purposes. The second workshop focused less on chronic diseases and more on social and economic conditions, and it was stated that gender-based analysis had to be employed. In both the first and second workshop there were very similar calls for better surveillance for the issues of violence and abortion. There was similarity in the lists generated in the first two workshops and those proposed in 1990, which May Cohen reviewed earlier today:

1) Violence against women
2) Abortion and access to abortion
3) Mental health — depression, stress, anxiety
4) Occupational/work/environmental hazards — multiple effects among each
5) Pain, chronic pain
    - fibromyalgia
    - chronic pelvic
    - migraine
6) Cardiovascular disease, cancers, other medical issues — surveillance is already conducted, but there is a need for more gender-based analysis of the data and to determine where enhancements can be made.

Methodologies

The discussion concerning methodologies focused on the fact that traditional datasets and baseline data are no longer sufficient to truly understand women's health. We need to look at other data sources and apply equal credibility to qualitative and quantitative data. LCDC has to understand that surveillance must go beyond disease-specific conditions, adopt a broader perspective and develop surveillance activities for specific subgroups, such as street youth, young women, elderly women, geographic distribution, ethnic groups and the Aboriginal population, as well as for non-traditional health issues, e.g., violence, abortion and accessibility. In terms of geographic distribution, the use of postal codes does not provide enough detail about remote communities, so another way of examining residence and isolation has to be found.

Data holdings: those participants who represent or manage specific databases were asked to give a brief description of the purpose of the database, populations covered in their databases, frequency of data collection, variables in the data set and limitations of the database, as follows.

Canadian Institute for Health Information

- Data related to health service providers — registered nurses, physicians and, in process, a database on non-registered nurses and non-registered physicians
- Hospital discharge abstract data
- National trauma registry
- Organ replacement registry — data on transplants, dialysis, etc.
- Therapeutic abortions database (hospitals only, excludes clinics)
- Chronic care database (Ontario)
- Databases related to national health expenditures
- Activities related to classification standards: ICD-9, new ICD-10
- Primary care

In terms of the methodologic issues that have been raised, it was noted that the timing for modifying existing databases managed by CIHI is very good because there is a review process under way, and so if changes are to be made now is the time to introduce them as consultations with the provinces/territories and hospitals are being held.

Statistics Canada

- Vital statistics database — currently enhancing discharge data, live births, still births, deaths by province
- Health and physical activity limitation survey (new) — emphasis on elderly women, personal care, quality of life issues, and health expectancy indicators
- Census — new questions asked regarding people living in long-term facilities to find out who they are, e.g., immigrants, people living on income supplements
- Feasibility studies linking vital statistics, cancer registry and morbidity files are being investigated; currently under contract from LCDC, Statistics Canada links live births and deaths; and LCDC and Statistics Canada have worked over the last two years to modify the information collected through vital statistics. Another project linked the 1986 census to tax files — followed deaths to examine income data, occupation and death. It was proposed that additional linkages could be undertaken to look at death, occupation and cancer and similarly from live births to census to mortality and morbidity data. These linkages could be done every five years with different samples, different geographic regions and for groups at risk, e.g., Aboriginals, immigrants, etc. In 1991, the Aboriginal People's Survey was conducted, and linkages to other databases are possible — before this can happen, there is a need to justify and provide support rationale for linkages.

The group felt that when organizations are looking at modifying their databases and/or their data collection instruments, the groups on whom data would be collected should be involved in the design and modification process. This would only strengthen the instrument and methodology, because much “inside” information could be gathered, for instance, what will work and not work for that group in terms of language, wording or a particular issue being asked about.

It was stated that it would be useful for CIHI to know ahead of time what changes are wanted so as to help during the negotiation process. Justification could be provided by trying to be more creative, e.g., hip and knee replacements — it will be possible to track people following their surgery through the trauma registry. Data are already captured on health records, and so an additional variable is not required, e.g., expand out of data collected at the hospitals, emergency rooms, ambulatory care (Alberta already collects this, and recommendations have been made for Ontario), home care. In terms of nursing homes, CIHI cannot mandate collection.

There are many women’s health issues that do not lead to hospitalization. We need to find a way to get this information and link it with other data. Standardization is another problem. There is a need to develop unique identifiers for linking purposes. Diagnostic codes are not always accurate. Conversion tables have been developed with physician data and claim data — many physicians are on alternative reimbursement schemes, and CIHI is looking at strategies for standardization.

Before we embark on new data collection, we must recognize that in many cases we are data rich, and often politics becomes the obstacle to gaining access to a database or linking databases, so that data are underutilized. There are enormous barriers in sharing data. The group strongly encouraged organizations, government departments and researchers to share data.

It is important to educate practitioners at hospitals in data collection and the need for proper documentation: often notes do not give enough detail and important information does not get captured. Different provinces have different problems, e.g., the use of ICD-9 codes: in Quebec, the union limits the number of codes they can report/use. In fact, anyone involved with data collection/data entry has to be well trained so as to ensure accurate recording of information.

Statistics Canada — Surveys

Health-related surveys at Statistics Canada include the National Population Health Survey (NPHS), which in 1994 was designed to be both cross-sectional and longitudinal, and involves data collection every two years. There are now plans to develop a national health survey every year, and the Community Health Survey would alternate with the NPHS. The design of this new survey would be cross-sectional, and it would have a large sample to permit regional and subprovincial level analysis. The focus of the context would be behavioural risk and physical measures. Statistics Canada uses focus groups to identify questions in areas that are sensitive for special groups.

The Census requires mandatory response and so does the post-census survey, the Health Activity Limitation Survey (HALS). It is the only survey to which selected respondents must respond.

Occupational health — trying to link occupation and mortality. The NPHS is trying to collect information on care giving and the multiple roles that people perform. Stress was a focus content in the 1994 cycle and will be part of the 2000 cycle. Violence data are obtained through the National Survey on Violence (a one-time survey), and the General Social Survey (GSS) has a violence cycle. If the GSS data and the NPHS could be linked then this would provide a very good database on violence and other health factors. A major limitation of surveys is that in most cases the Territories are excluded.

Issues continue to arise regarding validity, accuracy, sharing databases, data and dissemination of results. For example, the Cancer Registry exists at Statistics Canada, has been patient-oriented since 1992, is updated regularly, consists of good quality data and could be linked with vital statistics. Ontario collects information on only one cancer per woman, which is a limitation. Other programs have been developed, e.g., the National Breast Cancer Screening Program, and are individual-oriented to follow the person. The Enhanced Cancer Surveillance Program, 1991-1996 data, looks at occupation, etc., throughout lifetime and is ready for analysis. The Canadian Cancer Coalition was formed to link surveillance data, risk factors, treatment, drug factors, etc., and is supported by Health Canada, Statistics Canada, provincial agencies and volunteers. Expansion of the registries was encouraged.

Drugs and hormone replacement therapy have become an increased cancer risk. There are no data nationally. The group discussed the need for a surveillance system that would alert practitioners and women to changes in dosage levels of some drugs.

Abortion

Approximately 35% of abortions are conducted in clinics, and 65% in hospitals. Abortion data have been collected and reported to Statistics Canada/CIHI, but this reporting is very limited in terms of variables and is even more limited in the reporting from clinics in terms of variables and number of clinics supplying information. LCDC developed a statistical collection tool and conducted a pilot study with several of the clinics. The purpose of the pilot was to see, first, if one data collection program could be developed to serve several uses and, second, if the variable list could be expanded to provide data on occupation, socio-economic status, student status, educational level, working and child care, for example. Some of the clinics did not participate in the pilot because of fear, particularly regarding protests and shootings that have occurred in the past; however, some of the clinics are willing to participate in ongoing data collection. There are 13 clinics across Canada. Quebec is unique, in that some abortions are performed in physicians' offices and some in CLSCs, so it is difficult to determine exactly how many places are providing abortion services. There are different reasons why some clinics do not participate: no computers, the use of the data is a major concern, the staff time- justification of completing forms, often single providers, single operator and only one clinic.

Abortion information is generally perceived as dangerous. Clinics fear that the data would be used to target, harass and intimidate both clients and staff. We need to protect providers and patients. In terms of access issues, some women purposely choose to go elsewhere, e.g., not to the clinic or facility closest to them. Often it is unacceptable to ask some questions. Postal codes should be used to determine where the patient goes to seek abortion. There is no leadership in the area of abortion at the federal level, and it is perceived as lacking a coordinated approach to data collection and reporting. Also raised was that the lag time in submitting data and reporting by Statistics Canada is too long, and thus the reports are not really very useful. The pilot was able to turn around data analysis in a much faster time frame, and this was seen as very positive by the participating clinics.

Prince Edward Island — Advisory Committee for Epidemiology (ACE)

Various surveillance activities ongoing in PEI include communicable disease surveillance, reproductive disorders, cardiovascular disease, asthma, etc., in response to public needs. Coordination of efforts is needed at the national level, because of difficulty focusing on what priorities are. A national surveillance system initiative was developed to look at all surveillance being done, e.g., LCDC, CIHI, etc. Support was given to the establishment of a national women's health surveillance system and the approach taken so far, in terms of the consultation process and the questions/issues being put forward for discussion.

Input on Priorities Identified

The group went through the identified priority areas and made the following comments with regard to determining whether the existing data are currently sufficient, and identifying gaps in terms of priority areas and the lack of data — what needs to be done to improve the data and what type of analyses should be done.

Violence: In 1993, a Violence against Women survey was conducted, which should be updated. Also, in Toronto a pilot study (telephone survey) on violence during pregnancy was conducted. Women seem to be willing to talk about experiences of past exposure to violence, but it is difficult for them to talk about violence they are currently experiencing.

Population study — violence during pregnancy: 70% of violence against women occurs during pregnancy. The data are rich in NS, BC and NFLD, but there are no national level data. CIHI is trying to make databases more consistent — there are major barriers if they are not national, and standardization is difficult across provinces. CIHI negotiated additional variables for perinatal surveillance, and other data are collected, e.g., hip and knee with trauma registry. There is a need to marry additional information with abstract or by using unique identifiers. Violence should be defined to include not only physical but also emotional aspects — depends on the questions asked. Mental health is related to violence. Physicians and other staff require training to carefully collect data. The Royal College should be influenced to implement mandatory training.

With what LCDC already does, how can it be made better? Traditionally, reproductive health, breast cancer and Pap smear screening were the only women's health surveillance issues. Currently, there is still no comprehensive women's health surveillance, even though surveillance is expanding and now includes more coverage in cancer and some aspects of cardiovascular health. LCDC is basically organized by disease with the exception of the Bureau of Reproductive and Child Health and the Bureau of Operations, Planning and Policy.

The group discussed two or three issues or activities that should be undertaken.

Data Inventory

- The group stated that there was a need for an inventory of all existing databases before making final decisions on what amendments or additions need to be made to existing databases.
- LCDC has completed an inventory of its surveillance activities. Also, LCDC has established a dissemination division to ensure that the dissemination aspects of the existing surveillance systems are carried out. Each surveillance system requires a dissemination plan. Two national committees meet annually, the Advisory Committee on Epidemiology (ACE) and the Chief Medical Officers of Health, to discuss and help promote dissemination of information and issues of surveillance.
- Produce an annual report card on health status by vulnerable subgroups for dissemination. What is currently done in LCDC is not enough; as well, there should be cross-referencing with data put out by other organizations and departments.
- Discuss variables and indicators and their relevance for women's health, establish a core set and have the definitions standardized — for example, marital status is not relevant in understanding whether a woman has social support or not, thus it is not very important to ask about marital status.
- Produce a women's health report: the content should answer what we need to know, using a very broad definition of health, which includes the determinants of health, what constitutes health and how healthy are women who live in Canada. In addition, there is a need to look at how to mobilize data collection and data

assimilation from various sources, and to consider how the report will be disseminated, and not for research purposes.

- Regular activity of bringing data suppliers together may be useful, in the short term

In the next six months, what can LCDC accomplish within the priorities listed (content and methodology)?

For example, abortion — next steps, number of abortions, similar to unemployment rates, number of hours per week that women work outside of working hours — GSS, related to stress, etc., ongoing indicators, characteristics of subgroups.

Chronic pain — better coding in the works with the implementation of ICD-10, intensity measure — have you been diagnosed by health care professional with migraines expected to last six months or more, NPHS — migraine specific, when diagnosed — year 2000. Many people are not diagnosed by physician.

Priority area	*6 month schedule to be in Women's Health Report*	*Longer term - to make data collection more relevant*
Violence	• admissions to hospital • if pregnant or not should be recorded	• conduct another National Violence Against Women survey
Abortion	• include on data collection forms: access (woman's residence to facility); time to appointment • access by age/parity/gestational age	• negotiate with clinics to have comparable reporting
Mental health	• admission to hospitals: separate depression, schizophrenia and suicide attempts • suicide rates among Aboriginal population	• develop surveillance of pharmaceuticals and mental health

Occupation/Work environment	• report on time off work due to illness/stress • record how much time off due to illness; compare benefit packages available to women by type of occupation and compare with men	• merge data from different databases: economic, occupation, industry
Chronic Pain	• report on time off work due to migraine, back pain, repetitive pain • improve databases so this detail is collected • medication use vs narcotics • examine physician claim data for reason for visit	• define quality of life indicators • integrate qualitative data • quality of life is more than mental health and data collection and indicators must reflect this
Cardiovascular	• report on interventions women receive • what are the complications women experience? • when do women present with symptoms?	• rework questionnaires (data collection forms) so issues reflect differences between men and women - they have different issues • regional differences in interventions and strategies
Diabetes	• report on complication rate between men and women • work to identify Aboriginal and report by this • link diabetes data with dialysis data (work with CIHI)	• improve ethnicity variable • link cancer data with dialysis data

Cancer	• report on screening practices • examine environmental exposures, e.g., type of occupation and health outcomes • investigate cancer rate in occupations that are female dominant	• work with registries and Statistics Canada to ensure linkage of cancer file with mortality data • improve data collected at cancer centres, e.g., number of cancers per person and collect stage data • work to have screening included in fee schedule
Osteoporosis	• record fall as reason for admission • change discharge data forms to include where discharged to • collect data on function-ability of patient and report on type of falls and place, women have different types of falls than men	• undertake data collection on assistive devices and report on who gets what type

Methodologies (non-content priority area)

A consistent recommendation from all three workshops was for LCDC to develop a surveillance database inventory that includes all surveillance databases beyond the LCDC holdings. It has to include the data dictionary and all other relevant operation information about the database. Then, LCDC should charge a group of database managers and analysts to do ongoing review and evaluation of these databases. This group would also discuss strategies for reaching the marginalized population and how to effectively obtain surveillance data from these groups.

A second methodologic recommendation was for the women's health surveillance system and all other surveillance reporting from LCDC to be done according to gender-based analysis.

List of Workshop Participants

Penny Ballem
4500 Oak Street
Vancouver, British Columbia

Marie P. Beaudet
Chief, Health Vital Statistics Studies
Statistics Canada

Marsha Cohen
Centre for Research in Women's Health, University of Toronto and Sunnybrooke and Women's College Health Sciences Centre

Christina Fitzgerald
Canadian Institute for Health Information

Eva Grunfeld
Ottawa Regional Cancer Centre
University of Ottawa

Betty Havens
Professor, Community Health Science
University of Manitoba

Lorraine Ferris
Institute for Clinical Evaluation Sciences

Susan Kirkland
Graduate Program Co-ordinator
Department of Community Health and Epidemiology
Dalhousie University

Nancy Mayo
Clinical Epidemiology
Royal Victoria Hospital

Michael McCracken
President/CEO
Informetrica Ltd.

Diane Robson
Director of Data Services
Saskatchewan Cancer Foundation

Michael Shannon
Director General
Laboratory Centre for Disease Control
Health Canada

Louise Sanchez Sweatman
Canadian Medical Association

Lamont Sweet
Chief Health Officer
Department of Health and Social Services
Charlottetown, PEI

Konia Trouton
Coordinator, Population Health
Department of Family Medicine
University of Ottawa

Don Wigle
Laboratory Centre for Disease Control
Health Protection Branch
Health Canada

Russell Wilkins
Statistics Canada

Christel Woodward
Professor, Clinical Epidemiology and Biostatistics
Department of Epidemiology
McMaster University