

Report on the
NATIONAL
FORUM
ON 
BREAST
CANCER

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NATIONAL

FORUM

ON 

BREAST

CANCER

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MESSAGE FROM THE MINISTER

On November 1993, I addressed the opening session of the National Forum on Breast Cancer. It was a particularly meaningful way to begin my role as Minister of Health. I have a great personal interest in breast cancer and our government has given women's health issues a high priority. Canadian women deserve no less.

Launching this Report gives me great pride. As the product of a truly participatory process, it represents a significant step towards coordinated action on breast cancer in this country. Its message is clear, as is the path we must now follow.

Women with breast cancer, voluntary workers, lobbyists, scientists, health care providers, policy makers and private-sector representatives will all find something in these pages to help them move the agenda forward in a concrete way. Let us seize the moment. Let us build on the momentum of the Forum and remain true to its spirit.

I thank everyone who contributed to the Forum in any way, and I congratulate participants on their work and their thoughtful recommendations. Individually and collectively, you have helped lay the foundation for a vigorous and action-oriented partnership, and to open up exciting possibilities for addressing other major health challenges. I would like to reaffirm my Department's full support for this initiative as it enters a new and critical stage.

Diane Marleau
Minister of Health

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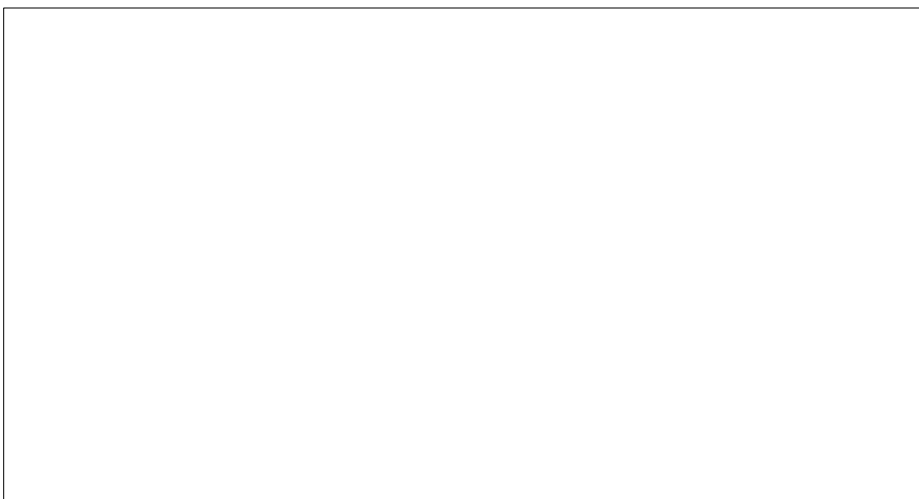
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I THE FORUM



The toll taken by breast cancer in Canada has been steadily climbing. Each year, about 16 000 women are diagnosed with the disease and well over 5000 die. Growing public awareness of the impact of breast cancer — on women, their families, friends and communities — is providing a new sense of urgency to efforts in the field.

“Group discussions were a stroke of genius, brought different proponents together bonded by common interest and served to deflect the initial impression of an inter-group adversarial atmosphere.”

The 1992 House of Commons Standing Committee report “Breast Cancer: Unanswered Questions” highlighted, among other things, the need for greater consistency in service delivery and more consensus on the issues. In its response to that report, the federal government identified a number of initiatives to address breast cancer, and pledged to support “a National Workshop to develop consensus on research, prevention and care.” Four national organizations — the Canadian Cancer Society, the National Cancer Institute of Canada, the Medical Research Council and the Canadian Breast Cancer Foundation — subsequently joined forces with Health Canada to sponsor this landmark event, which took place in Montreal in November, 1993.

Breast cancer is a national problem that involves widely diverse constituencies. Despite their varied perspectives, all share the sense that more can and must be done to address such issues as the growing demand for improved research funding, and the need to provide women with access to information, effective screening and treatment programs. All increasingly recognize that responsibility for moving the agenda forward must be a shared one, with consumers, health providers, the private sector, every level of government and non-governmental agencies playing a part.

With this in mind, a major objective of the Forum was to lay the groundwork for broadly-based partnerships that would catalyse action and mobilize resources on this serious health problem. Accordingly, the 650 participants who attended the event represented the full range of interests, and included researchers, clinicians, family physicians, volunteers in cancer agencies, government program and policy people and — perhaps most importantly — women with breast cancer and their families, who made up approximately one-quarter of those present.

Conference sponsors hoped that the presence of individuals from throughout the breast cancer community would promote broad ownership of the recommendations, and a common commitment to collaborative endeavours in the future. They looked to the Forum to yield a clearer definition of the problems, and practical ideas and suggestions for resolving them.

The Conference Organizing Committee was made up of representatives from the sponsoring organizations and the subcommittee chairs, and its meetings were chaired by Health Canada.

In broad terms, the National Forum on Breast Cancer was designed to identify key issues to be addressed in relation to four major theme areas: namely, *Research, Prevention and Screening, Treatment and Care*, and *Support, Advocacy and Networking*. Recognizing that the scope was too wide to be met in the course of a three-day meeting, the Conference Organizing Committee struck four subcommittees to undertake preparatory work in the four theme areas, and a fifth to assist with the scientific program. Their task prior to the Forum was to summarize existing knowledge, seek input from all parties involved — including women with breast cancer and the general public — and recommend what priorities and directions should guide the future activities of research agencies, universities, governments, advocacy groups, volunteer agencies and health care institutions.

This process was one of several innovative features of the Forum designed specifically to promote full and meaningful dialogue and exchange of ideas. In the five months leading up to the event, the subcommittees obtained input from a total of about 130 people in working groups. The subcommittees' role was to receive and summarize the literature, seek out new data, discuss emerging issues and draft background papers, including recommendations. These papers formed part of a comprehensive briefing package provided to all participants, which also included selected readings and other background materials on the subject themes.

This careful provision of pre-Forum opportunities for representatives from different constituencies to interact in the subcommittees and working-group settings not only resulted in the integration of different perspectives into the draft papers *prior* to the event, but also facilitated the development of shared directions *at* the Forum.

Another key feature of the Forum was the emphasis placed on relatively small multipartite discussion groups. Each participant spent a total of more than six hours (over three sessions) in one of 41 very lively discussion groups, reviewing and refining the initial subcommittee recommendations, with the support of discussion facilitators and rapporteurs. Following each session, group conclusions were summarized, translated and distributed to the members themselves, as well as the appropriate subcommittee and the Conference Organizing Committee. The subcommittees' pre-conference work was therefore continued into the Forum, with chairs and members joining discussion groups on the floor and integrating ideas from these into their

final reports and recommendations which were summarized in a plenary session on the closing day of the Forum.

A pre-Forum survey conducted by the Subcommittee on Support, Advocacy and Networking provided useful insights into the views of women with breast cancer on the issues under review; survey respondents were women receiving either active or follow-up care. The findings helped highlight the lack of attention to the psychological dimensions of breast cancer, both in research and in the design and delivery of treatment and care services. To ensure that this would be remedied in future, sponsoring organizations went all out to include participants whose expertise was derived from the daily experience of living with breast cancer. The attendance of women with breast cancer and lay volunteers was made possible by support from the federal government, the Canadian Cancer Society and contributions from corporations in the travel and hospitality sectors through the Canadian Breast Cancer Foundation.

The Forum featured a number of international and Canadian speakers on breast cancer. They provided a mix of poignant stories of personal encounters with the disease and highly technical research papers. Poster sessions and oral presentations rounded out three full days of activity, learning and sharing.

A particularly moving event at the Forum was a balloon ceremony, “Catch the Wind,” in which the children and grandchildren of two women who had died from breast cancer released 14 brightly coloured balloons, each representing one of the 14 women who die of breast cancer each day in Canada. Few who attended this ceremony came away unmoved by the experience. In addition, there was a photo exhibit, “Faces and Stories,” portraying 19 Canadian women who had died of breast cancer and including a brief bilingual text about each woman. The exhibit also included letters from the provincial and territorial government leaders, outlining initiatives undertaken by those governments to address breast cancer.

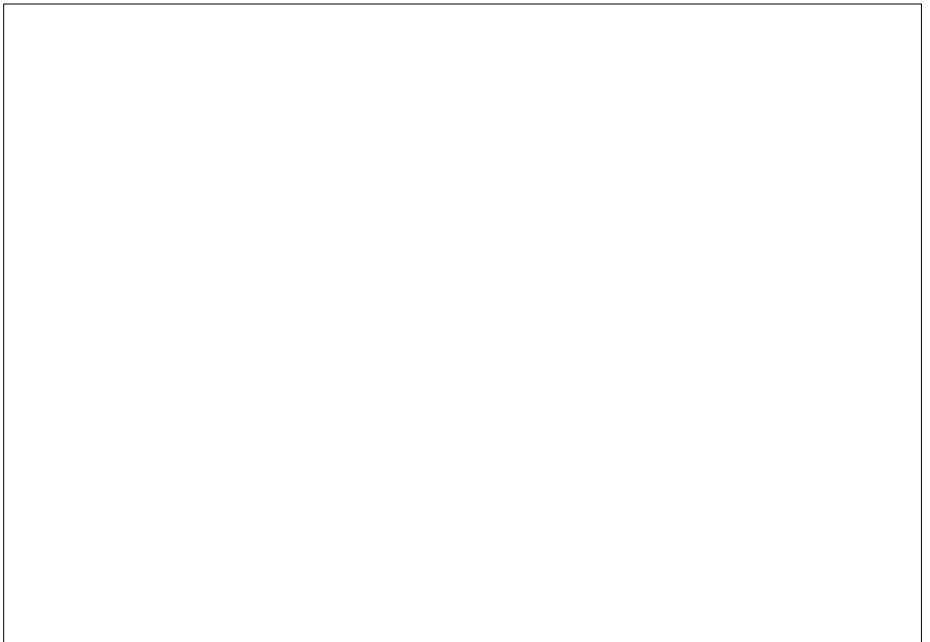
The Forum has been variously described as “a changing experience,” a “watershed” and a “truly historic event for women with breast cancer.” It generated a new level of mutual respect among the many groups in the breast cancer community and opened the way to improved communication and collaboration across the board. The palpable sense of optimism, remarked upon by many participants, eased the way to agreement on several controversial issues. Moreover, there are encouraging signs that the energy, spirit of cooperation and commitment that marked the event have since taken firm hold; some of the working groups that assisted the subcommittees now have a life of their own as “mini-networks.”

The concerns of women dealing with the day-to-day reality of breast cancer were clearly, forcefully and articulately stated. Many researchers, health care providers, government representatives, advocates and volunteers left with a fresh perspective on the issues and with renewed hope that the partnership approach will strengthen the hand of the breast cancer community in fighting this disease, over both the short and the long term.

It has been said that the voice of women with breast cancer tended to predominate at the Forum. Perhaps this was because they were being heard formally for the first time. At the same time, however, important new alliances were forged between existing groups, many of whom seldom meet to exchange views. These included clinicians and basic scientists, volunteer cancer agency personnel, health policy analysts and others. It is hoped that future gatherings will permit the fruitful exchanges that began at the Forum to continue among these groups.

Throughout the event, a number of common principles emerged — they included the need for better communication, collaboration and coordination at all levels, and for greater consumer involvement, the importance of taking all dimensions of the disease into account and need for consistency in clinical practice. These have been further elaborated in the body of this report.

II GUIDING PRINCIPLES



As the Forum progressed, a number of themes or central ideas repeatedly surfaced in the discussions. These ideas, restated below as guiding principles, are viewed as being of fundamental importance to all future study and action in the field of breast cancer. They are:

- *Communication at all Levels*
- *Consumer Participation*
- *A Holistic Approach*
- *Collaboration and Coordination*
- *Consistency in Clinical Practice (Guideline Development).*

• *Communication at all Levels*

A universal theme at the National Forum on Breast Cancer was the need for better communication, not only among groups and individuals in the breast cancer community, but also with the public at large. In the view of participants, improving communication across the board would be one of the single most effective ways to advance the national breast cancer agenda.

Prominent among participants' concerns in this area was the physician-patient relationship, particularly as it relates to the provision of information and shared decision-making. Also, participants pointed to the fact that many families find it hard to find out about diagnosis, prognosis and treatment options. Their stress can be compounded by feelings of helplessness and

the difficulty of communicating their own feelings to the member with breast cancer. Concerns in these areas led participants to recommend that training in communication skills be provided for health professionals — both in-service and as part of their basic medical education — as well as support for women and their families to communicate effectively which will enable them to acquire the information needed for treatment decision-making. Forum participants also made a strong case for more research into communication issues, stressing in particular the need to better understand women's concerns at different stages of the disease.

They further called for improved communication between health care providers and support networks, between referring physicians in the community and major treatment centres, and between researchers and clinicians. A recurrent theme was the need for better dissemination of research findings. In the view of Forum participants, this involves not only ensuring that the results of studies reach all potential users, including health professionals, policy-makers and women, but also that they are made available in plain language and an accessible format.

Participants recognized that providing the public with accurate, helpful information about breast cancer is a complex undertaking. It requires that culturally appropriate materials and messages be targeted to different audiences through a variety of channels, including the media, schools and workplaces. They emphasized the importance of keeping women with breast cancer, health professionals and the public informed of new developments in all areas, including prevention, screening, treatment, research and public policy.

The Forum represented an opportunity to open up the lines of communication among the many groups involved in breast cancer, so that current and future breast cancer issues may be addressed in a comprehensive way. The concerns of women, in particular, were heard; however, there remains room for improved communication among health providers, be they in the policy area or in clinical settings, as well as between clinical practitioners and members of the research community, and between advocacy groups and volunteer agencies.

• *Consumer Participation*

In shaping a future agenda for breast cancer, no group is more important than women who have been diagnosed with the disease. They are uniquely qualified to contribute to discussions on the delivery of sensitive, appropriate services in prevention, screening, treatment and care, and on the future directions of research.

The message from the Forum was strong and clear: ensure that all discussions and decision-making on breast cancer issues are participatory and collaborative, with all concerned groups included and that lack of funds does not prevent women with breast cancer from taking part in conferences, workshops and other key events.

There was general agreement that inadequate consultation with women has contributed to a number of gaps in current service delivery models and approaches. To ensure consideration of women's needs, concerns and perspectives in the future, Forum participants felt that consumer participation must become a routine part of service planning and delivery. The importance of the

consumer's role is reflected in their recommendations on the services and support women need along the full continuum of care — including clear information, shared decision-making and respect for their needs and concerns. It is also reflected in the Forum's call for women to be involved in the processes that govern research funding and priority-setting, and to have an opportunity to influence research protocols and methodologies, including ethical standards.

Participants felt the Forum itself provided a model for future interactions and exchange among the various groups working on breast cancer issues. They saw the experience as offering a practical demonstration of what can be achieved when all concerned groups have an opportunity to bring their views to the table, and a firm foundation for future deliberations and decision-making.

• *A Holistic Approach*

Consumers and other concerned groups insist that a more holistic approach to the treatment and care of breast cancer is needed — one that explicitly acknowledges both the non-medical dimensions of the experience for women and their families, and the fact that psychosocial needs vary at different stages of the disease. Indeed, there is a widely-held view, shared by many Forum participants, that psychosocial as well as physical factors influence the development and progression of breast cancer. For example, in a pre-Forum survey carried out by the Support, Advocacy and Networking Subcommittee (SAN), 38 per cent of the respondents named stress as a contributing factor to their disease. This and other related hypotheses need careful study, given that the “mind-body connections” remain poorly understood. How is breast cancer linked to personality, coping strategies, the degree of stress in a woman's life and her socio-economic circumstances? Is survival positively related to the degree of social support a woman receives?

What is certain is that breast cancer has a profound effect on every aspect of a woman's life — her relationships, her self-image, and indeed her view of life itself. On the negative side, anxiety, depression, hopelessness and altered sexual health are common experiences for women over the course of the disease. Added to these can be an array of practical problems — being unable to keep up with housekeeping and home maintenance, long waits for treatment, loss of income, difficulty communicating with family and health care providers, and, all too often, confusion and uncertainty over treatment choices. With access to good information about breast cancer and strong peer and family support, however, many women say the experience has helped to deepen their emotional and spiritual life and strengthen their personal relationships.

Consumers point to the need for qualitative research to investigate the psychological, social and spiritual needs and concerns of women with breast cancer and their families, with special attention to those from different social and cultural backgrounds. Such research could make a major contribution to the design of appropriate, responsive treatment and care models that emphasize quality of life as well as physical outcomes — models that are based on respect for the patient's needs and wishes as the disease progresses, and that provide timely and supportive treatment and care, ready access to information and shared decision-making.

In such models, the woman with breast cancer is recognized as an important member of the treatment team, with the right to make informed choices, to ask for a second medical opinion, and to combine conventional treatments with complementary therapies should she so wish. Participants pointed out that women at high risk for breast cancer and those being screened for the disease or awaiting biopsy also have particular needs and concerns, and that studying these would contribute to more responsive service delivery in these areas.

There was broad consensus that investigations into the psychosocial dimensions of breast cancer should receive much higher priority in the future research agenda, and that a concerted effort should be made to incorporate the results of such research into the design of information, treatment, care and other services to women and their families.

• *Collaboration and Coordination*

Breast cancer is an issue of concern to a diverse array of groups and individuals, each with particular concerns and priorities. Forum participants emphasized the importance of working in a partnership approach, and the need for improved coordination of effort at all levels.

They pointed, for example, to the distressing effects on women of receiving services in a fragmented manner, often from a series of caregivers who are not in contact with each other. What is needed, in their view, is an integrated, multidisciplinary approach to medical and non-medical treatment and care. The woman must be seen as a key member of the team, working closely with the family physician, surgeon and oncologist. These health professionals, in turn, need to coordinate their efforts with those of other team members along the continuum of care, including nurses, social workers, dietitians, physiotherapists, psychologists, support networks, volunteers and pharmacists. This is an approach that would allow women's varying needs — medical and non-medical — to be met at different stages of the disease.

In the area of research, participants called for coordinated cross-disciplinary studies, reflecting the many interrelated facets of breast cancer. In fact, the new directions set at the Forum explicitly call for research initiatives to be collaboratively conceived and implemented. Participants also pointed to the need for better coordination and linkage of the data held in cancer registries, billing systems and clinical databases across the country, and for the establishment of a nationwide network of tissue banks and computerized pharmacy record systems in all provinces/territories. The appropriate use of data from these sources would, they felt, contribute to a better understanding of the factors influencing breast cancer development, and allow for the evaluation of various models of care. Participants stressed, however, that treatment of breast cancer should always be personal and individualized, and that coordination activities should never be carried out in a way that would depersonalize women or compromise the confidentiality of their health records.

Finally, participants called for a nationally coordinated public education and awareness effort to ensure that Canadian women receive a uniform message on breast cancer. At the same time, they emphasized the importance of tailoring the information to the needs of different audiences.

Consolidating resources and information, bridging gaps between the various interests in the breast cancer community, strengthening old alliances and building new ones and, where necessary, modifying approaches and procedures to reflect this new spirit of collaboration — these are key themes underlying many of the recommendations emanating from the Forum.

• *Consistency in Clinical Practice (Guideline Development)*

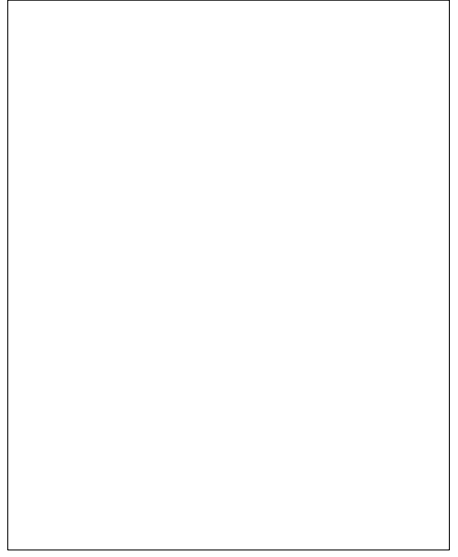
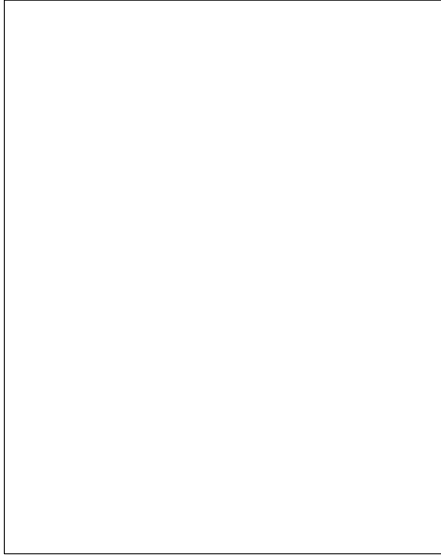
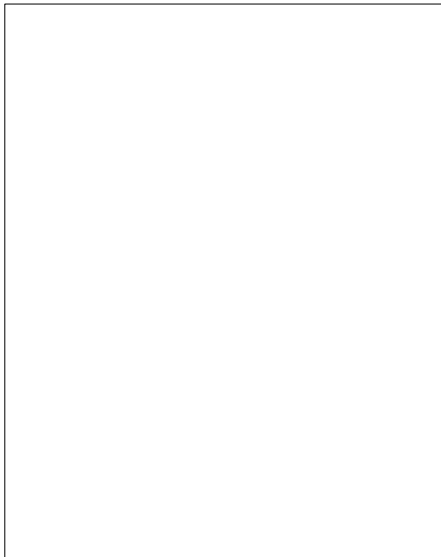
Clinical practice patterns can vary widely from one physician to another — in the initial diagnosis of breast cancer, for example, or in surgical approach. Participants saw this as a matter of considerable concern. In their view, national practice guidelines are needed to guide treatment and care at all stages of breast cancer. Defined as “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances,” clinical practice guidelines can help to promote informed decision-making by patients and physicians and enhance professional learning, patient education and patient-physician communication.

Participants also felt that a structure should be in place to encourage the adoption of practice guidelines by practitioners and that, in general, all physicians and other care providers should be up to date on new medical research and procedures.

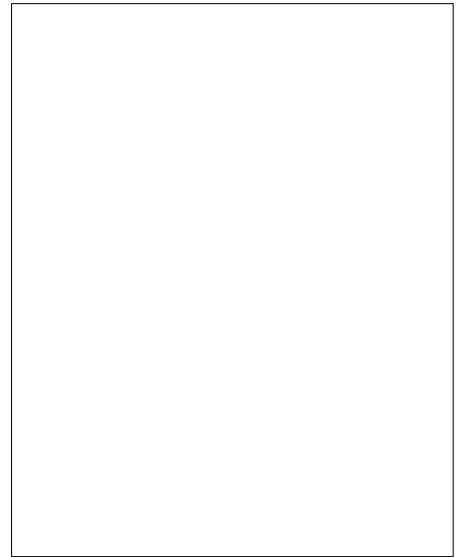
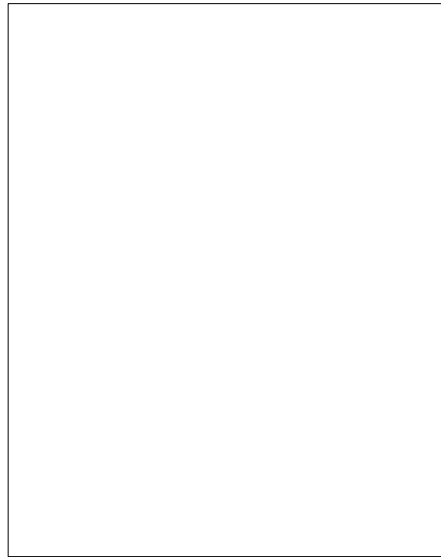
As a basis for the development of breast cancer guidelines in Canada, participants identified the following as attributes of good guidelines: the guidelines should be supported by scientific evidence; they should be developed through a multidisciplinary, participatory process; they should be consistent across similar clinical settings and circumstances; they should be stated clearly and unambiguously and allow for some clinical flexibility; they should be subjected to independent review during their development, and regularly updated in light of emerging experience and new evidence; finally, there should be an appropriate infrastructure in existence for guidelines development, implementation and evaluation.

There was general recognition that the development of credible guidelines on a national scale requires the participation of many sectors, including provincial health ministries and cancer organizations, the federal government, professional organizations representing physicians, nurses and related health professions, national associations representing oncology disciplines, and groups representing the affected community.

III THEMES



“The quantity of information was impressive, and the warmth and humanity and the will to find a solution to this plague.”



Prevention

Screening

Treatment and Care

The Research Process

The Network

Prevention – Issues

Canada has one of the highest rates of breast cancer in the world. In fact, breast cancer incidence has risen steadily in this country since the 1960s, especially for women over 50. A Canadian woman today has a one in nine chance of getting breast cancer during her lifetime.

Aside from being a female, the strongest risk factor is age. Other factors known to put a woman at risk include living in an affluent Western country, having a mother and sister who have had breast cancer, starting menstruation very early, having a first child after age 30, and never having been pregnant at all. Still, up to three quarters of women with breast cancer have no known risk factors besides their gender and their older age. There appears to be widespread ignorance among women about the fact that risk increases with age — only a third of women know that advancing age is a major risk factor for breast cancer, and a large proportion of those who do *not* know are in older age groups.

There are striking differences in breast cancer incidence among populations. For example, Japanese women living in Japan are much less likely to get breast cancer than their North American counterparts; however, women of Japanese origin living in North America get breast cancer at North American rates. This suggests that dietary, environmental, social and cultural factors play an important role in breast cancer development. However, the research to date has been scanty and sometimes controversial, due at least in part to the difficulty of accurately determining and measuring dietary and social patterns and assessing environmental exposures.

There was strong support among Forum participants for a concentrated research effort in these areas, with special emphasis on suspected risk factors that may be modifiable. More information is needed on the interactions among various potential biological, dietary and environmental influences and on the interactions among such factors as radiation and environmental toxins in the prenatal and pre--adolescent periods. This, in turn, requires a better understanding of the basic physiology and biology of the normal breast — including in adolescence, which is suspected as a time of high vulnerability — and of the series of mutations occurring in the breast epithelium which underlie cancer development and progression.

“Expand the range of research to include environmental causes.”

It is also important to clarify the normal functioning of ovarian hormones and their connection to breast cancer, the effects of oral contraceptives and hormone replacement therapies, and the effect of environmental contaminants on estrogen and other hormones.

The apparent links between pregnancy and breast cancer risk has led some researchers to suggest that simulating pregnancy may be a way of lowering risk. There have also been suggestions in the literature that prolonged use of the drug tamoxifen may help to prevent breast cancer. Clinical trials to explore the use of this drug as a preventive measure are currently under way, but these will not provide information to woman under age 60 who are at average risk of breast cancer. The question of hormone manipulation, by whatever means, remains highly controversial and a matter of widespread concern. Participants called for full and open debate on all the implications of this approach to prevention and for the discussion to include input from women.

Apart from dietary and hormonal factors, there are other avenues for research. For example, the potential effects of occupational exposures and chemical toxins on breast cancer incidence and development have not been adequately studied. Well--designed studies are also needed on the links between psychosocial and socio--economic factors and breast cancer risk. So, too, are investigations into the influence of physical activity and body mass index on breast cancer development and how these interact with known and suspected risk factors, the value of antioxidant vitamins and minerals, and the role of alcohol. A better understanding of all these issues would assist in the development of preventive approaches that are solidly supported by scientific evidence.

In fact, the greatest barrier to the development of effective preventive strategies is the current lack of understanding about how breast cancer is caused. While it is true that dietary and lifestyle changes — such as reducing fat consumption and alcohol intake — have known benefits for other chronic diseases, it is nevertheless important to provide a sound scientific basis for advocating or implementing any widespread change in women's behaviours in order to prevent breast cancer.

Despite the problems inherent in telling women they are at risk without also being able to tell them what they can do about it, there is a strong case for the development of a nationally coordinated breast health awareness strategy, beginning with what is known about breast cancer risk and incorporating new information as research results become available. Such a campaign would help to increase women's understanding of the issues in the wider context of health promotion and disease prevention. Consistent with the principles of health promotion, it would avoid blaming the victim and make women at all levels of society and from all cultural backgrounds more aware of what is currently known about breast cancer risk, what areas are being researched and, further, what their personal level of risk is and what they can do to either minimize or manage that risk.

Prevention – Recommendations

For Study

1. To develop a comprehensive national strategy aimed at understanding the causes and reducing the incidence of breast cancer in Canada. In particular, to encourage collaborative interdisciplinary research on dietary, environmental and other suspected risk factors, with special attention to those that are potentially modifiable, and on women's exposure to risk factors throughout their lives, including during the developmental years. Areas for study would include, but not be limited to:
 - the effect of diet, alcohol and other possible lifestyle influences on breast cancer development, with emphasis on the effect of dietary and lifestyle modifications on breast cancer risk — for example, in migrants, aboriginal peoples, occupational groups — and on the behavioural determinants of dietary and lifestyle change
 - the influence of environmental contaminants such as organochlorines on breast cancer development, and the role of occupational exposures in breast cancer risk
 - the development and assessment of biomarkers for dietary and environmental exposures, as well as for early events in carcinogenesis or breast cancer risk
 - hormonal influences, including childbearing and breastfeeding patterns and the administration of hormone therapies
 - the development of a full understanding of the genetic basis of breast cancer, including both hereditary and non-hereditary forms of the disease.
2. To determine how information on breast cancer risk and prevention can be effectively communicated between researchers and clinicians, clinicians and patients, researchers and the media, and the media and the Canadian public, with particular attention to the need to communicate effectively with populations that are hard to reach. The research would include:
 - conducting qualitative studies to investigate the perceptions and information needs of women at risk, as a basis for developing and evaluating information materials and services

- determining how different health care providers interpret risk and how they communicate risk to their patients — for example, the risk associated with hormonal therapies
 - identifying strategies for communicating effectively with women who are at risk for breast cancer, as well as those with benign breast disease.
3. To examine whether and to what extent such factors as place of residence, the availability of services, socio-economic status and information from health care providers influence the choices women make when they find they are at high risk for breast cancer.
 4. To ensure that clinical interventions involving hormone manipulation include a long-term follow-up component, and that pharmaceutical and other companies routinely fund independently-conducted post-marketing surveillance of the drugs and devices they produce, and that the results of such studies are made available to all concerned parties.

For Action

5. To promote formal discussion on the desirability of using hormone manipulation for the prevention of breast cancer, including a consideration of the social and ethical implications of this approach.
6. To develop a nationally coordinated health promotion and breast cancer awareness strategy in the context of the women's health platform. The objective would be to inform women (including those in hard-to-reach populations) about known risk factors and ongoing research in breast cancer in a helpful and healthy manner — i.e., with all communications avoiding a “blame-the-victim” approach.

Screening – Issues



The benefits of screening mammography appear to be age-specific: there is strong evidence that mammographic screening reduces breast cancer deaths among women aged 50 to 69. However, mammography has not been adequately evaluated to determine its impact on breast cancer mortality among women aged 70 and over. In women under 50, the evidence remains controversial: while many randomized studies have included women in this age group, the summary of all the data has thus far failed to show any significant decrease in breast cancer mortality. Of particular note is the fact that mammography in women with a strong family history of breast cancer has not been specifically evaluated.

Unfortunately, controversy over whether mammographic screening can improve mortality among younger women has tended to dominate the discussion, leading to confusion among women about whether they should be screened and at what age. Certainly, it has left many women in the 50-to-69 age group with the mistaken impression that mammography is not beneficial for them. This is a matter of considerable concern.

Given that there is now wide consensus on the benefits of mammography screening for women aged 50 to 69, it is important to devote energy to reaching this target audience with a suitable message, and to ensure that screening is readily available and accessible to these women. There would be no benefit at this time in having a further consensus conference to deal with target ages and intervals of mammography. Instead, efforts should be focused on informing women about what is currently known in a balanced fashion that allows them to make their own decisions. For the women in other age groups — especially those who may be at higher risk — accurate information should be provided so that they can make an informed choice about mammography screening.

"I hope to meet with the participants of my province soon and discuss how we will find a way to implement the breast screening program for women 50-69."

Communicating effectively with women in all their diversity is a dual challenge, involving the target audiences on the one hand and health professionals on the other. There has been some research on the barriers and incentives to mammographic screening, with emphasis on access and awareness. These community-oriented studies have suggested, among other things, that it is difficult to reach women who are socially or economically disadvantaged, and that there should be more emphasis on planning and evaluating programs which encourage

wide participation. What is clear is that any research into communication issues in the area of breast cancer should include social and cultural variables that are meaningful to the group being studied.

The role of physicians in encouraging women to be screened has not been fully researched, but the fact that most Canadian women visit their doctors regularly seems to provide an opportunity for intervention. With this in mind, it is important to ensure that primary care physicians are aware of the recommended age groups and screening intervals.

How can mammography screening best be delivered to those women whom it will benefit? The National Workshop on the Early Detection of Breast Cancer in 1988 proposed that high-quality screening be made available to all appropriately aged women throughout the country — including indigenous women and those living in rural areas — through programs and dedicated screening sites. There should also be good quality assurance — that is, the highest standards in terms of image quality, the qualifications of screening personnel, interpretation, timely follow-up and pathology review. This implies the need for monitoring on an ongoing basis.

Seven provinces and one territory have instituted organized screening programs, using a variety of approaches, delivery modes and target age, but most programs lack the resources to reach all women in the groups targeted. Provinces/territories with screening programs should be encouraged to continue them. The differences between these programs is a potential source of useful information — for example, to further our knowledge on age groups to be screened or the inclusion of clinical breast examination along with mammographic screening. To ensure that such programs are effective, an ongoing comprehensive assessment strategy is required, including an evaluation of the approach being used in each jurisdiction to encourage both initial and repeat screening.

Clinical breast examination (CBE), when carried out on its own, detects breast cancer, but the evidence of its effectiveness is not of the same quality as that related to mammographic screening. The justification for routinely including CBE with mammography — as some provincial/territorial programs currently do — is that mammography results can be negative even when breast cancer is present, especially in young women. Unanswered questions about CBE include: to whom should it be done, and how often? who should carry it out, and what technique should be used? how can CBE techniques be evaluated? how can CBE skills be upgraded? how do the outcomes compare in screening programs that combine mammography and CBE, and those that offer mammography alone? Would CBE be a cost-effective addition to mammographic screening programs?

With regard to breast self-examination (BSE), there is no published evidence that this practice reduces breast cancer deaths. However, women who perform BSE tend to have smaller tumours at diagnosis, and there are indications that its effectiveness in detecting tumours may be a function of how well it is performed. According to the results of a survey conducted by the Support, Advocacy and Networking (SAN) Subcommittee, over 60 per cent of women with breast cancer reported detecting their own lumps, using BSE or by chance.

Because many believe that BSE has a potential to detect early cancers, it has become a regular feature of public health programs for women. Those who endorse the practice see it as an act of social empowerment; others regard it as a potential, but unproven, intervention to which rational guidelines should be applied. Basic questions remain unanswered. These include: is BSE effective? when should it begin? who should be encouraged to do it? how should it be taught? what is the psychological impact of practising BSE on a regular basis?

Some researchers are working to identify genetic markers for breast cancer risk. These studies are being carried out in “breast cancer families” — those in which a very high number of female relatives have breast cancer. The aim is to pinpoint the gene or genes that indicate a very high risk for breast cancer. While this research is important, it must be kept in perspective. Only about two to five per cent of current breast cancers are thought to be attributable to a hereditary predisposition.

A major issue, then, is what to do with the information on genetic markers once it becomes available. Discovering that they have a genetic marker may complicate the lives of many women and undermine their quality of life. Some of the questions to be answered include: who should be screened for these genes, and at what age? what advice should be given to women found to have a genetic marker for breast cancer? what should they be told before having the test? what is the psychosocial impact on a woman and her family of knowing she has the gene? how can we, as a society, prepare to deal with the privacy and ethical issues that genetic screening will inevitably raise?

It is important to have educational programs for both women and health care providers, informing them about hereditary breast cancer, risk assessment and predictive testing, and how to deal with this information. Moreover, there must be extensive study of the ethical, legal and quality-of-life issues involved in testing for hereditary breast cancer.

Screening – Recommendations

For Study

7. To foster the use of a national database derived from mammographic screening programs across the country. This would allow for a comparative analysis of costs and outcomes and, in particular, facilitate an assessment of the potential benefit, essential components and ideal method for delivering clinical breast examination (CBE).
8. To examine the differences in outcomes between provincial programs with varying policies for screening women under age 50, again using a national database.
9. To conduct research aimed at improving, refining and evaluating the suitability and efficiency of imaging techniques, including the use of digitization procedures for analysis of mammograms and the potential role of magnetic resonance imaging (MRI).
10. To determine how medical schools across the country currently teach and assess the performance of clinical breast examination (CBE) in their curricula, and to recommend improvements where necessary.

For Action

11. To provide a level of resources that would enable provincial screening programs to reach at least 70 per cent of the women in the 50-to-69 age group, and as close to 100 per cent as possible, and to devote more resources to raising public awareness and directing appropriate information materials to this target group.
12. To ensure that mammography screening in all provinces and territories is carried out within the context of an organized program which has the following essential components:
 - a population-based outcome goal
 - information about the target population
 - special emphasis on hard-to-reach groups (including rural communities)
 - meticulous quality assurance, including equipment and interpretation
 - outcome data and analysis
 - information systems and linkages

- a woman-centred focus
 - excellent coordination, with high-quality diagnosis and follow-up.
13. To develop and deliver information about target age and intervals of mammography screening to women in a balanced and culturally sensitive fashion that allows them to make their own decisions. This involves:
- promoting collaboration at all levels, but particularly between organized screening programs and voluntary agencies, on the delivery of appropriate public education messages about mammography screening
 - developing an information package for use in the primary care setting with women under age 50 and over age 70, to help them make a truly informed choice. Among other things, the information would address the questions of premenopausal women with a family history of breast cancer in a first-degree relative.
 - ensuring that all education materials are developed within a multidisciplinary setting, with strong input from individuals skilled in communications and from user groups.
14. To hold a consensus meeting of all professional and volunteer agencies involved in the teaching of breast self-examination (BSE) and consumer groups, to identify a uniform message for delivery throughout Canada. Messages carrying the same basic content could then be tailored to the needs of particular audiences.
15. To develop a policy with respect to genetic screening. The process could be initiated by holding a workshop, or by establishing a committee with broad representation, including consumer advocates, researchers, funding agencies, health professional associations, bioethicists, and representatives of government and the legal profession. The task would include:
- determining the societal impact of predictive testing, with input from those potentially affected — including women with a family history of breast cancer — on the possible risks and benefits involved
 - evaluating the role of genetic counsellors and their integration into the health care system
 - examining confidentiality issues related to genetic screening and the likely impact of a positive test result on such things as a woman's insurability, employment and job advancement, eligibility for immigration and her family relationships, and considering whether there should be legislated protection for women in such areas as privacy, insurance and misuse of data
 - ensuring that a careful study of all relevant issues has been undertaken before genetic testing is made available on a widespread basis.
16. To discuss, in a multidisciplinary group, the best means of disseminating appropriate information to both women and physicians once genetic tests become available.

Treatment and Care – Issues

For women with breast cancer, the journey from diagnosis through treatment and care can be frightening, lonely, painful and difficult. Clearly, the ultimate goal is to be cured, or if this is not possible, then to ensure that quality of life, dignity and self-respect are upheld at every stage along the continuum of care.

This has considerable implications for the health care system in terms of how services are organized, what treatments are offered, how women's options are explained to them, how therapies are given, how pain is controlled, and what role families and support networks play throughout the process. In short, for the woman with breast cancer, the treatment phase implies much more than just chemotherapy, radiation or surgery — she needs the best possible medical care, delivered in an organized way by an integrated team of health professionals and support workers, with proper consideration of all her needs and concerns.

The difficult decisions women face lie at the foundation of their partnership with their physicians, and the objective should be to strengthen that partnership in all ways possible. When they are first being treated in hospital for breast cancer, women cannot access support groups on their own, as can outpatients. The SAN Subcommittee Survey report points out that legal issues may prevent untrained volunteers from visiting patients in hospital under some circumstances, and identifies this as an area where physicians, hospitals and volunteers must organize their effort so that the systems “works” for the patient.

In the treatment and care of breast cancer, action is implied in the following broad areas: supportive care, team work, practice guidelines and professional education.

Supportive care refers to those services that help a woman deal with breast cancer from the moment of diagnosis on. They include providing her with appropriate information — on the physical and psychological aspects of the disease, as well as on her treatment and support options — encouraging her and her family to share in the decision-making about treatment, and ensuring that she has timely access to treatment. Supportive care addresses a woman's informational, physical, emotional, social, spiritual and financial needs.

“At last, an opportunity for professionals and patients to begin a process, discuss patients' issues, and feel you're being listened to!”

The gap between women's information needs and many service providers' perceptions of those sometimes leaves women poorly informed about their treatment options and their prognosis, and feeling excluded from the decision-making about their own illness. Physicians have differing views on how much patients need or want to know about their disease, and how much the information helps them once they have it. One concern noted was the tendency of some health professionals to dwell on treatment issues, while shying away from women's social and psychological needs and from their real anxieties — body image and fear of death, for example. Most have not had any training in communication skills, and many have limited experience in shared decision-making on treatment. Moreover, health professionals sometimes distance themselves from women with breast cancer and their families just when their support is most needed. Without the necessary support and information, many women are left to make decisions in a confused emotional state, and families may be at a loss to know what is going on or how they can best be of help. The dynamics of the patient-physician relationship need to be clarified. What types of exchanges help to increase patient satisfaction and quality of life? Do decision aids really work? How can physicians learn to sensitively share the control with their patients? There have, in fact, been well designed studies which have identified some of the characteristics of effective physician-patient communication. This knowledge needs to be shared with health care providers and researchers in the area of breast cancer.

Women's needs for information and other support at the various stages of breast cancer must be better understood. The period between the first suspicion of breast cancer and referral to an oncologist or cancer centre is a time of high stress, yet patients feel little is done to help them cope. Some women — for example, those with low literacy levels or from different cultures — can feel particularly alienated, as the means and materials used to communicate with “mainstream” patients are often ill-suited to their needs.

Patients need to be included as important members of the treatment team, and the efforts of that team should be carefully coordinated at every stage, in a way that responds to patient needs and concerns, be they medical or non-medical. Pain relief and palliative care are two areas in which patient preferences and concerns about quality of life should be heard and respected.

Another major concern in the treatment and care of breast cancer is the lack of a coherent set of clinical practice guidelines. Variations in physician practices can make women anxious and uncertain about whether they are receiving the most current or appropriate treatment, whether they should seek a second medical opinion, and what other options, if any, are open to them. Also, women newly diagnosed with breast cancer are sometimes approached to enter clinical trials. They should have balanced information on what is available in the area of clinical research in order to be able to make an informed decision.

The proper investigation of a suspicious lump, the need for quality control of mammography, the relative merits of lumpectomy versus mastectomy, the determination of optimal radiation dosages, the circumstances in which high-dose chemotherapy and autologous bone marrow transplantation are justified, the management of pain, nausea and vomiting, the basic requirements for supportive care — these are among the many issues that require the

development of clinical practice guidelines. Such systematically developed statements about the appropriate health care for specific clinical circumstances would contribute immeasurably to improved practitioner and patient decision-making.

An allied problem is that of ensuring that guidelines, once established, are actually followed. What factors influence physician behaviour in this area? Studies show that awareness of the guidelines' existence, their availability, their credibility and a variety of sociocultural factors all play a part. Some physicians perceive guidelines as "cookbook" medicine, not tailored to individual needs; others maintain that the adoption of guidelines can lead to loss of autonomy.

These are major challenges, which suggest that the guideline development process should be broad, participatory and continuing, with provision made for regular review and evaluation. Physicians must directly participate in and "buy into" the process. They should also ensure that patients and families have access to any guidelines that are available, bearing in mind that guidelines are not hard-and-fast rules, but are intended to assist both physician and patient with decision-making. Such measures would help to introduce more consistency into the treatment and care process, and increase patients' confidence in the system.

A strong indicator of some patients' lack of confidence in the medical system is the continuing interest in alternative or complementary therapies. Over a third of women in the SAN Subcommittee survey said they had turned to such treatments. Many women feel that alternative therapies address their emotional and spiritual needs and their wish to be actively involved in boosting their immunity, fighting the disease, coping with fears and minimizing the negative effects of treatment. It is important to understand why women adopt various alternative therapies, to evaluate the impacts of such therapies on breast cancer patients and to examine how these might interact with conventional therapies.

Clearly, change is needed if the treatment and care offered to breast cancer patients across the country is to be supportive of their needs, consistently high in standard, and delivered in a coordinated way by a team of appropriately trained health care providers, with the patient playing a central role throughout.

Treatment and Care – Recommendations

For Study

17. To continue research aimed at improving the outcome of therapy, including research on:
 - adjuvant therapy for node-negative and node-positive disease
 - dose intensification — for example, high-dose chemotherapy and autologous bone marrow transplantation.
18. To examine the psychosocial dimensions of breast cancer and the mind-body connections that may influence the course of the disease. This should include research on:
 - the physical, psychological and spiritual problems encountered during all phases of breast cancer, including diagnosis, recurrence and the terminal phase, in order to provide optimum care to patients and their families.
 - the influence of psychological and social factors on quality and quantity (survival) of life at various stages of the disease, using measures specific to breast cancer and, when feasible, prospective longitudinal design
 - the effects of supportive communications on women's coping ability and on the physical progression of their disease
19. To evaluate programs that teach physicians and nurses to assess and enhance the psychosocial status of women with breast cancer.
20. To identify the information needs of women at all stages of breast cancer, and to evaluate communication strategies designed to meet those needs. This would involve:
 - examining the experience, concerns and information needs of women from varying cultural backgrounds and their families
 - exploring how physicians' disclosure patterns can affect patients' health and well-being

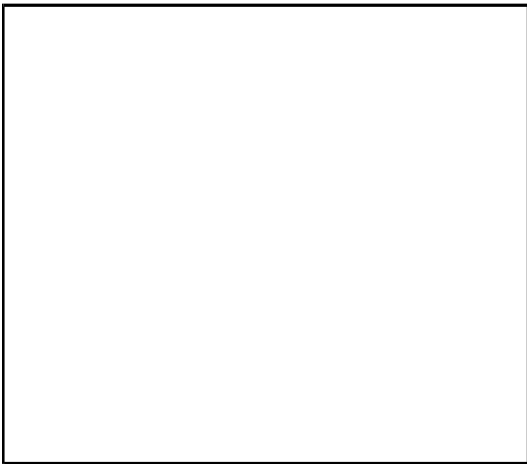
- identifying supportive communication strategies helpful to the families of women with breast cancer, bearing in mind that different families have different information and support needs
 - identifying ways of helping both women and their physicians cope with their feelings about the experience of dealing with breast cancer
 - identifying ways of improving both health professionals' and patients' communication skills, so that both are better equipped to give and receive information.
21. To study the physician-patient relationship as it relates to decision-making about treatment choices and quality of life. This includes:
 - identifying interactions that lead to increased patient satisfaction, knowledge and quality of life, and further exploring the process of patient and physician decision-making
 - identifying effective ways of informing patients about the potential risks and benefits of treatment, clarifying values and enhancing patients' ability to carry through with treatment decisions
 - evaluating consumer aids designed to involve patients in treatment decisions. This would include developing appropriate outcome measures, given that decisions are frequently value-laden and that there are no right or wrong choices.
 22. To define and evaluate the effectiveness of non-conventional cancer treatments available in Canada and examine how these interact with conventional medical therapies.
 23. To clarify what factors influence a woman's decision to abandon or continue conventional medical therapy.
 24. To determine what treatment and care services are available in various parts of the country, how accessible these are, and what mix of services best enhances the dignity and autonomy of women and their families.
 25. To include an evaluation component in all new treatment and care interventions.

For Action

26. To ensure that information is readily available and accessible to women with early or advanced breast cancer and their families. This includes:
 - developing and disseminating, through a variety of channels, comprehensive information packages dealing with diagnosis, treatment, rehabilitation and supportive care
 - placing special emphasis on information materials targeted to the interval between diagnosis and treatment, and to the time when the woman learns that the cancer has recurred or metastasized
 - developing and maintaining a mechanism for the coordination of all breast cancer information exchange initiatives.
27. To give high priority to the development and evaluation of communication skills training that targets practising health professionals — particularly oncologists and surgeons — and health sciences students. Such training should be based on respect for individual rights and choices and the importance of shared decision-making. This involves:
 - working with medical professional associations and women with breast cancer to explore innovative models for multidisciplinary communication skills education
 - modifying undergraduate, graduate and post-graduate training and including communication skills training in medical schools, hospitals and continuing medical education programs
 - providing communication skills workshops for patients and their families, with special attention to ethno- cultural background and those disadvantaged by virtue of age, education, socio-economic status and place of residence.
28. To develop and evaluate clinical practice guidelines for breast cancer management, including pain control/management as a high priority. This includes:
 - ensuring that the guidelines development process is national (bearing in mind that cancer treatment is a provincial responsibility)

- ensuring that patients as well as health care professionals have access to clinical practice guidelines
 - developing mechanisms for the evaluation of clinical practice patterns, including an assessment of the outcomes of care — for example, patient satisfaction, quality of life and cure.
29. To promote an integrated team approach to medical and non-medical care and treatment, with the patient, primary caregiver, family physician, surgeon and oncologist as team members, and to recognize that coordination among physicians, nurses, social and home-care workers and the woman's support network is essential to personalized and appropriate care.
 30. To ensure that women with breast cancer have timely access to treatment and care, including appropriate emotional and psychological support. This implies the need to develop models for coordinated breast cancer care at a regional level, and to ensure a level of funding that enables standards of care to be maintained.
 31. To ensure that women who opt for non-conventional forms of treatment feel able to discuss this with their physician in an atmosphere of openness and without prejudice to their medical care.
 32. To develop and promote a statement on patient rights, which could include provisions on access to information, informed consent and the right to a second medical opinion.

The Research Process – Issues



Canadian research on breast cancer to date has been based on a model involving investigator-initiated projects reviewed for quality by peer-review panels. Granting agencies have recently allocated resources to targeted research efforts (e.g., the Canadian Breast Cancer Research Initiative). There have also been efforts in other areas that have the potential to contribute to our knowledge of breast cancer (e.g., studies undertaken by the Centre for Behavioural Research and Program Evaluation of the National Cancer Institute of Canada (NCIC) and the Canadian Genome Analysis and Technology Program initiated by the Medical Research Council (MRC)). Nevertheless, some groups in the breast cancer community have expressed concern about the way in which research priorities are set, its strong biomedical focus — often at the expense of other research dimensions — the lack of input from women with breast cancer on research directions and approaches, and the generally “opaque” nature of the funding process.

The goal should be to ensure that breast cancer research is of scientific, ethical and social value to all who have an interest in breast cancer. In particular, women with breast cancer are calling for a greater voice in the decision-making and in the research processes; researchers, for their part, are insistent that the scientific rigour of the peer-review process be maintained.

“It was good to get researchers, other health care professionals and survivors together. They need to interact. Women need to know what research is going on and researchers need to know the concerns of women.”

Clearly, including a wider range of perspectives at all stages of the research process would improve both the validity and the utility of the research results. The challenge for the breast cancer community is to make the research process more open, inclusive and accountable while still maintaining the highest research standards and ensuring that Canada retains its competitive standing in the international arena.

It is also important to ensure a balance between basic research and preventive, epidemiological, environmental, organizational, behavioural, psychosocial and evaluative studies that can contribute to a broader view of the causes, cures and consequences of illness. The research community must be willing to foster collaborative and innovative approaches, and to welcome the participation of a broader range of disciplines and perspectives.

At present, large data sets of potential value to breast cancer research sit in provincial billing systems, cancer registries, clinical databases and pharmacy records across Canada. Better

coordination and linkages among these databases would clearly facilitate research in the epidemiological and other fields. However, explicit means to ensure and maintain the privacy of individuals must be in place prior to the use of these databases.

Better communication among all stakeholders, both in and outside of the research community, would help to generate new ideas and fresh approaches. Among other things, this means developing research ideas in partnership and sharing research results as they become available, not only with peers, but with clinicians, policy-makers and the community they are intended to benefit. The implications and applications of research — and, indeed, the rationale for carrying out particular studies — should be widely publicized, in a form that the lay public can understand.

Increased breadth of research, more open and participatory processes, an expanded pool of researchers, increased training and support for researchers from a wide range of disciplines, better dissemination of research findings — these measures all imply the need for additional funding for breast cancer research, as well as a reallocation of existing funds in keeping with reordered priorities. A major challenge of the future will be to raise public and corporate awareness of the need for sustained support for breast cancer research.

The Research Process – Recommendations *For Study*

33. To broaden the scope of breast cancer research to encompass priorities, opportunities and approaches identified at the Forum, including research into:
 - breast cancer *causation* and biology in the following areas: diet, lifestyle and environment; hormones; biology/molecular pathology; inherited predisposition
 - breast cancer *detection, diagnosis, treatment and supportive care* in the following areas: health services; imaging; quality of life; psychosocial services; therapeutics; and communication
 - public policy related to breast cancer.
34. To explore ways of ensuring participation by a broadened base of concerned individuals and groups in the research process, while at the same time maintaining scientific rigour. Possible approaches include sponsoring a workshop on models for lay participation in the research process, and exploring models currently being tested in other countries and in other research domains.

For Action

35. To increase the financial contributions of Canadian governments to cancer research in general and breast cancer research in particular, and to have these linked to a fixed denominator such as the Gross Domestic Product (GDP), making them comparable to the contributions provided by the governments of other industrialized countries.
36. To generate public support for increased breast cancer funding and stimulate corporate and private donations to the breast cancer research funds, by distributing the new research directions emanating from the Forum to all levels of government, community-based organizations, the media and relevant professional associations.
37. To prepare and maintain a detailed public inventory of breast cancer research undertaken in Canada and funded by Canadian institutions and organizations, including pharmaceutical companies.

38. To promote an explicitly collaborative, multidisciplinary and participatory approach to breast cancer research. This includes:
- identifying women with breast cancer and their representatives — including those from diverse cultural communities — for membership on committees responsible for the establishment of research policies and priorities
 - establishing mechanisms in national funding agencies that ensure continued dialogue among researchers, clinicians and women with breast cancer and their families and advocates, with the aim of identifying research priorities.
 - facilitating participation by researchers with varied interests and a broader range of disciplines
 - preparing a register of all individuals and organizations involved in breast cancer research, for the information of all partners in the breast cancer community
 - examining guidelines on collaborative research developed in other spheres, and sponsoring model projects on collaborative research into breast cancer.
39. To consider how coordination and linkage of existing databases — including cancer registries, billing data and clinical databases — can best be achieved, and to improve methods for extracting and analyzing information from these databases, with due regard for the privacy of individuals. Other initiatives to improve coordination of epidemiological research and health services might include:
- establishing a nationwide network of tissue banks
 - ensuring that all provinces maintain computerized pharmacy record systems that can provide data for use in epidemiological studies.
40. To increase the pool of scientific investigators studying breast cancer, by:
- ensuring that adequate funding is available for the training and support of breast cancer researchers
 - actively encouraging the involvement of young investigators, women and other under-represented communities
 - incorporating women’s perspectives into the training of biomedical and social scientists, basic scientists, clinicians and policy-makers.
41. To make research results widely available and readily accessible to potential user groups — for example, health professionals, researchers, policy-makers, women with breast cancer. This includes:
- explicitly earmarking resources for the dissemination of research findings and their implications and applications

- publishing up-to-date information about breast cancer research results in an accessible form and language
- exploring the feasibility of establishing a clearinghouse to liaise between the research and lay communities
- examining how information from new research, especially clinical studies, can best be transmitted to physicians, and studying the impact of such information on subsequent practice patterns.

The Network



– Issues

“No woman should be left to herself, alone, without information when she is diagnosed.”

For too long, women with breast cancer have been a silent constituency in debates about the disease. As a result, the agendas that now dominate research and policy-making have evolved without significant consultation with those most affected. The National Forum on Breast Cancer provided a formal and very public opportunity for women with breast cancer and their advocates to place their concerns on the table. In this sense, the meeting represented a major break with tradition.

Women newly diagnosed with breast cancer face perplexing decisions. In a state of shock and often inadequately informed about their treatment and care options, they may make choices they later regret. At the time of diagnosis, few women grasp how confusing the options are, even to health professionals. In the pre-Forum Survey conducted by the SAN Subcommittee, respondents said that what they had most wanted at the time of diagnosis was information. For example, they needed to know more about their medical condition, the possible physical symptoms of the cancer, the treatment choices available and the possible negative effects of treatment. But such information can be hard to come by. Communication barriers and time constraints limit the physician’s ability to act as a resource. Women interested in alternative and holistic treatments may feel particularly frustrated, as many health professionals are wary of non-conventional approaches. And, although in some communities there are volunteer services in place to provide patients with information and support, these have not always been well coordinated and few professionals direct women to them. For all these reasons, women often find themselves overly dependent on their physicians.

Support groups address problems for which women feel no other assistance is available — their sense of being isolated, stigmatized and discriminated against, for example, and their feelings of anger, self-blame and guilt. Thirty-seven per cent of the respondents to the SAN Subcommittee Survey said they had participated at some point in a support group for women with breast cancer. The main benefits (cited by approximately 80 per cent of support group participants) were the opportunity to find out that others felt the same way as they did, to get more information about breast cancer and its treatment, and to receive encouragement and reinforcement. However, some communities have no support groups, leaving a gap in vital non-medical services. Increasingly, women with breast cancer have moved to create their own groups for emotional support and advocacy. The resulting patchwork of volunteer services needs better

coordination, with the more traditional agencies playing a revitalized role alongside the newer consumer-driven support and advocacy groups.

Women and their families are often forced to bear the costs of travel, wigs and prostheses, medical devices needed for treatment, and psychotherapy and physiotherapy services. Almost half of the women in the SAN Subcommittee survey reported having had some expenditures for medical therapy in the previous year. Many women also face the loss of significant relationships, which can add greatly to the burden of their illness. Women also seek greater control over their treatment options. For example, those living in remote areas sometimes have to make their decisions based on concerns about travel or separation from family, supportive friends or work. Moreover, because the opportunity to enter a clinical trial often comes at the time of diagnosis, when women with breast cancer are highly vulnerable, they may decide to enrol, or to refrain from enrolling, without fully appreciating the implications. In the pre-Forum survey and at the Forum, women urged the health care and voluntary service sectors to pay greater heed to women’s psychological, emotional and spiritual needs.

In addition, women with breast cancer need to have increased visibility, an independent voice and a mechanism for advocacy. Forum participants discussed the formation of a national umbrella organization that is community-based and survivor-driven to represent women with breast cancer, including members of various social and cultural communities. This organization

“Support the network who has the trust of the women’s community.”

would work in partnership with researchers and clinicians towards the renewal of cancer care, treatment and research systems in Canada. Its objectives would be to ensure that women’s concerns are addressed in institutions involved in cancer care — governments, the medical community and the private sector — and that women participate in all areas of cancer policy and planning, including the development and distribution of information, screening and detection programs,

the delivery of treatment and care, the education of health professionals about women’s needs and concerns, and breast cancer research. It could eventually be expanded to include other groups concerned with breast cancer.

The SAN Subcommittee report concluded as follows: “Canadian women who are concerned about breast cancer have begun to create a strong collective voice in the events that will determine their care and ultimately affect the quality of their lives and those of their daughters. Together, Canadians can change the legacy of breast cancer.”

The Network – Recommendations

For Study

42. To evaluate the impact of providing social support in various forms — for example, through mutual aid groups on the progression of breast cancer and on the psychological well-being of women with the disease.
43. To assess the influence of advocacy groups on the orientation of breast cancer policy.



For Action

44. To develop a national network of breast cancer support and advocacy groups that can provide an independent voice for members of the affected community. The network would be community-based and survivor-driven, with broad representation from among women with breast cancer. Its objectives would be:
 - to provide a vehicle for advocacy for research, treatment, information and services that meet the needs of the affected community, as well as giving women with breast cancer greater visibility in public forums
 - to work with existing research, treatment, policy and fundraising bodies to improve the care of women with breast cancer
- to provide members of the affected community with accurate up-to-date information

- to encourage communication between women and other groups concerned with breast cancer, both at the community level and across the country
- to improve public awareness of breast cancer and the issues that affect women living with the disease
- to improve the quality and length of life of persons with breast cancer.

Sunday, November 14

Master of ceremonies: Ms. D.C. Kirkpatrick, Health Canada

07:30-18:00	Registration
09:00-09:45	Inaugural Ceremony Addresses by the Honorable Diane Marleau, Minister, Health Canada, Dr. Christine Collin, Assistant Deputy Minister for public health, Ministry of Health and Social Services, Quebec and representatives from sponsoring organizations and survivors
09:45-10:30	Overview Presentation <i>Canadian Perspectives on Breast Cancer: Challenges for the Future</i> Dr. Marie-Dominique Beaulieu, Associate Professor, Department of Family Medicine, Université de Montréal
10:30-10:45	Health Break
10:45-11:15	Opening Conference Ms. Sharon Hampson, Family Entertainer, Sharon, Lois and Bram
11:15-12:30	Plenary Session: Prevention and Screening Chair: Dr. Heather Bryant
12:30-14:00	Lunch and Poster Sessions
14:00-15:15	Plenary Session: Treatment and Care Chair: Dr. Mark Levine
15:15-16:30	Plenary Session: Support, Advocacy and Networking Chair: Ms. Sharon Batt
16:30-16:45	Health Break
16:45-18:00	Plenary — Research: Chair: Dr. Ron Buick
18:00-20:00	Welcome Reception

Monday, November 15

Master of ceremonies: Dr. L. Slotin, Medical Research Council

07:00-08:45 Group Discussion: Networking

09:00-10:30 Group Discussion: Series I — Issues

10:30-12:00 Plenary:

The Early Breast Cancer Trialists' Collaborative Group (EBCTCG): Overview of Adjuvant Therapy of Breast Cancer
Professor Richard Peto, Professor of Medical Statistics and Epidemiology, Oxford University, UK

Psychosocial Issues and Life Cycle Concerns of Women with Breast Cancer

Dr. Wendy Shain, Psychologist working in cancer care and rehabilitation, Long Beach, California, USA

12:00-13:30 Lunch

13:30-15:30 Oral Presentations: Clinical Research, Epidemiology and Risk Factors, Screening Issues, Supportive Care, Treatment

15:30-15:45 Health Break

15:45-17:15 Plenary:

Prospects for Biological Therapy of Breast Cancer
Dr. Marc E. Lippman, Director, Lombardi Cancer Research Center, Professor of Medicine and Pharmacology, Georgetown University Medical School, Washington, DC, USA

Opportunities for Research on the Prevention of Breast Cancer
Dr. Maureen Henderson, Professor of Epidemiology and Medicine, Head, Cancer Prevention Research Program, Fred Hutchinson Cancer Center, Washington, USA

17:25-19:00 Dinner

19:00-21:00 Group Discussion: Series II — Priorities

Tuesday, November 16

Master of ceremonies: Ms. D. Lamont, Canadian Cancer Society

- | | |
|-------------|--|
| 09:00-10:30 | Group Discussions: Series III — Action Strategies |
| 10:30-10:45 | Health Break |
| 10:45-11:45 | Panel: Relations with the Media
Moderator: Dr. Robert Buckman, Toronto Bayview Regional Cancer Centre

Panel Members:
Marilyn Linton, Life Editor, Toronto Sun
Pamela Martin, BC TV
Patsy Pehlman, Executive Producer, “Morningside”
Dr. Danièle J. Perrault, Medical Director, Ontario Breast Screening Program |
| 11:45-13:15 | Lunch |
| 13:15-14:15 | Panel: Private Life and Confidentiality in Health Care
Moderator: Pierre Beaudry, Consulting and Audit Canada

Panel Members:
Luc Deschesne, Hôpital Saint-Sacrement, Université Laval
Paul-André Comeau, President, Commission de l'accès à l'information du Québec
Eugene Oscapella, Consultant, Privacy Commissioner's Office of Canada
Hilary Craig, Survivor |
| 14:15-14:45 | Health Break |
| 14:45-16:15 | Plenary: Presentation of Subcommittee Chairs' Reports and Closing Remarks |

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APPENDIX

3. Application Form for Attendance

IV A FINAL WORD

Conceived as an inclusive, participatory event, the National Forum on Breast Cancer provided the first-ever opportunity for members of Canada's breast cancer community to come together to share their ideas and concerns and their respective visions for the future. In the weeks and months since the event, many participants have enquired about the report on the Forum.

They and their organizations sense that a new era of partnership has begun. They recognize that a formal document, highlighting their collective concerns and charting broad new directions for the breast cancer issue, can serve as a valuable checklist for future activities.

This report represents a distillation of the main areas of consensus at the Forum. It draws on a number of sources, including position papers prepared in advance by the four subcommittees, major Forum presentations, reports on the discussions that took place on the floor, and formal

"This is a start. We have achieved an enormous amount, but as long as it continues after the conclusion, we can take some credit for it."

and informal feedback following the event. It is not a "government document," even though its production has been financed by Health Canada. Its ownership, and the responsibility for what happens next, lie with those who attended the National Forum on Breast Cancer and, as applicable, their organizations. It is up to each participant to formally review the 44 recommendations and the major themes and ideas emanating from this landmark event, and to see how, in our respective spheres, we can help to advance the national agenda in keeping with the spirit and the new directions set at the Forum.

The hope is that consumers, researchers, health professionals, government and private-sector representatives will all find something of value in this report, be it a concrete activity their organizations can undertake, an issue they can research, or simply some ideas about new ways of thinking and doing business.

Many of the recommendations in this document are broad in scope, and may be better characterized as long-term goals. Others pinpoint highly specific actions that can be undertaken almost immediately. The report provides merely a "snapshot in time" of an evolving process; already, events have begun to overtake some of its recommendations. This is as it should be. The momentum is there and the bridge-building that began in Montreal is well under way. If sponsoring institutions, participants and their organizations continue to take the messages of the Forum to heart, Canada can look forward to a period of unprecedented and sustained progress in breast cancer — one in which duplication of research, services and effort is minimized, patient needs and welfare drive decision-making, competition among institutions gives way to collaborative endeavours, and research efforts focus on *all* the dimensions of breast cancer.

There have been calls for representatives of the breast cancer community to sit down together again at an appropriate time to review what progress has been achieved since the Forum. Such a stocktaking exercise will help to keep all partners on track. Some of the questions to be answered at that time could be: what progress have we made in developing clinical guidelines? are consumers playing a meaningful role in the research process? have we succeeded in increasing public and private-sector funding for breast cancer? do all provinces/ territories have screening programs? is the public now better informed about the issues? are families receiving the support they need? is the treatment and care process more patient-centered?

The breast cancer community has set itself an agenda that is at once idealistic and realistic: idealistic, because some of the Forum's recommendations are somewhat visionary in nature; realistic, because for the first time women with breast cancer — the ones whom it is all about — have been admitted to the process.