

**Setting the Stage for the Future:
Understanding the Information and Support Needs
of Women with Cancer in PEI**

Stakeholders' Meeting

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Canadian Cancer Society **Société canadienne du cancer**

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STAKEHOLDERS' MEETING OVERVIEW AND GROUP RECOMMENDATIONS

A stakeholders' meeting was held on 22 June 2011 to which approximately 20 people attended representing the volunteer sector, survivor population, professional organizations, health, government, advocacy, health charities, and research.

Dr. Colleen MacQuarrie of UPEI presented the findings from *Women and Cancer: A Survey of Survivors*. This survey was undertaken in April 2011. Over 500 women survivors of breast or gynecological cancers who had been diagnosed in the past five years were mailed a survey. The response rate was 32%. Data from a focus group of women who met the same criteria were also presented.

Following the presentation of research findings, stakeholder representatives were asked to form groups according to their interest in responding to one of the following three areas for discussion:

- Economic issues
- Fears
- Information / communication needs

Groups were evenly distributed with six to eight participants forming each group. Discussion was to focus on three questions leading from resolution to action. The three questions were:

1. What can be done?
2. How might it happen?
3. Who might be involved?

ISSUES

Each group was to consider age as a mediating factor in each issue.

1. Economic Issues

Issues to stimulate discussion: a) slipping into poverty during treatment and not coming back out
b) Poorer women more likely to have recurrence or spread of cancer. Also consider age: Women over age 70 deserve the same level of health care as younger people and they also have specific needs that aren't being addressed. What about the issues for women who are under age 40? How might their needs be accounted for?

- A. Participants in this group felt that relieving the costs of cancer treatment drugs was a do-able action. Steps were identified to ensure that survivors are informed of the provincial drug plans and services provided by pharmaceutical companies.
 - a) Survivors should be fully informed of all drug treatment options, not just the ones that they can afford. Clear information should be provided to ensure that family also is aware of options.
 - b) Survivors should be automatically enrolled in the programs on referral from the family physician or medical specialist.
 - c) The current system utilizes an opt-in approach requiring survivors to know about the programs. The suggestion is that the system should implement an opt-out approach so that all survivors would receive all services or referral to all services unless they choose otherwise-- they opt-out. Involvement in this proposal would be the provincial pharmacy, the Cancer Treatment Centre (CTC), the Cancer Patient Navigator (CPT), medical professionals, and pharmacists.
 - d) Another do-able action was to advocate for catastrophic drug coverage. The working group suggested that raising awareness of this issue has broader application than only to cancer survivors and required a social/political response. Community activists such as those with the PEI Health Coalition, seniors' advocates, and the offices of the Canadian Cancer Society (CCS) might be involved in this solution.
- B. The CTC is piloting a "screening for distress" instrument and will address some financial concerns through that mechanism.
- C. Advocating for an extension of Employment Insurance benefits for survivors was identified as an action to be taken. Survivors report that the current number of insured weeks does not reflect the time span of a cancer treatment journey. The CCS was identified as an organization that might be involved in that issue.

- D. Increasing awareness of existing services such as wigs and prosthesis was identified as an issue in which the CCS might be involved.
- E. The working group on economic issues felt that the negative economic impact of illness was an issue broader than cancer survivors specifically and broader than could be dealt with through health channels alone.

2. **Fears (Medical and Personal)**

Issues to stimulate discussion: a) about 40% of respondents expressed less than “very satisfied” with how their fears were dealt with by medical personnel b) many women did not see formal avenues for dealing with their personal fears. Also consider age: Women over age 70 deserve the same level of health care as younger people and they also have specific needs that aren’t being addressed. What about the issues for women who are under age 40? How might their needs be accounted for?

- A. Participants in this group felt that communication was a route to combat women’s fears. A better job could be done to increase awareness of existing support programs. The group saw the CPT and social workers might be involved in this issue.
- B. Making medical staff aware that women are less than satisfied with how medical personnel deal with their fears was a do-able action. This could be accomplished through a number of routes including:
 - a) survivor presentations to medical schools or professional meetings
 - b) increasing awareness of community support programs such as Cancer Connection.
 - c) training of medical/nursing, other students to effectively respond to this need
 - d) undertaking research to identify specific fears so as to inform effective strategies.
- C. The working group felt that involvement of the CPT, more recognition from the mental health system such as Hospice and homecare, and awareness of the End of Life Coalition, were routes to address fears. Researchers might also be involved in increasing understanding of this issue.
- D. Understanding the fears of post-treatment and long term survivors should be addressed. These fears encompass the fields of medical, emotional, informational, and reoccurrence fears. This issue might be addressed by the CCS, CTC, Cancer Registry, non-governmental organizations, and support groups.

- E. Addressing cultural differences in the cancer experience was identified as an actionable issue. Screening for breast and gynecological cancers may not be part of some cultures. Increasing awareness among various cultures about the acceptability of screening were seen as involving the multicultural and newcomers associations on the Island.
- F. Ageism was seen as an issue that required attention. Screening programs and increased attention to the cancer threats to women over age 70 would address the issue.

3. **Information/Communication needs (asking for help, getting help)**

Issues to stimulate discussion: women are looking for clear and accessible information about their diagnosis, treatment, etc and about what supports are available to them. Also consider age: Women over age 70 deserve the same level of health care as younger people and they also have specific needs that aren't being addressed. What about the issues for women who are under age 40? How might their needs be accounted for?

This working group proposed that a “process map” describing how information flows and how it could flow would assist in ensuring women had the information they needed when they needed it. The CCS, CTC, and government and community resources might be involved in process mapping.

Information needs of younger cancer survivors might be achieved by linking with others.

Identifying the information needs of long term cancer survivors was suggested. The CCS, UPEI, health, and primary care systems might be involved in this issue.

Pre-treatment information needs to address the high anxiety that survivors feel even before they are in contact with the CTC or Prince County Hospital Oncology. The same high quality information, services, and supports should be available for survivors of gynecological cancers as are currently available for breast cancer survivors. One suggestion was to either adapt or develop kits for survivors of gynecological cancers on PEI. Models for such exist from the current breast cancer work and from work done in New Brunswick and other provinces. Other suggestions were for a one page information sheet to be distributed by physicians with contact numbers and addresses for information sources such as the CCS or websites. This could be distributed using the same pathway as is currently followed for women diagnosed with breast cancer. In that case the breast cancer kit is attached to the pathology report and given to the survivor at the time of diagnosis. Those involved in this might be the CCS, the health system, physicians, pathology lab, Medical Society, and partnerships beyond those currently established with breast cancer survivors and support groups. UPEI was also identified as a route to providing increased information or communication.

The group recognized the high volume of work of the single CPT position that serves all of PEI. The solution is to develop a network of informal community based cancer patient navigators across PEI who link with the formal CPT. A peer information model is available from New Brunswick and Newfoundland-Labrador. The CCS, CTC, and partnerships might be involved in taking action on this suggestion.

Key Messages

- Women over age 70 have unique needs that require attention
- Increased awareness of information and resources is needed
- Networking opportunities are important
- A formal mechanism is needed to respond to individual needs
- There is a mechanism to work through doctors but it has not yet been achieved. It is important to keep health professionals informed.