

Building on the evidence: creating a women's cancer strategy

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New Brunswick Breast Cancer Information Partnership Inc.



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The New Brunswick Breast Cancer Information Partnership (NBBCIP):

- Initiated regional collaboration
- Built upon research about women's cancers (breast, cervical, ovarian and uterine) in Atlantic Canada
- Expanding service and support to provide to underserved populations – increased organizational support



Overview

- 2008 profile of women's cancers in Atlantic Canada by the Atlantic Centre of Excellence for Women's Health
- This research was the foundation of the *Atlantic Invitational Think Tank on Women's Cancers*, held in March 2008.



Overview

- The Think Tank brought together Atlantic Canadian health professionals, community agencies, policy makers and survivors to discuss access to services for cancer information and support.

Overview

- New Brunswick has begun the integration of gynecological cancers into its breast cancer network
- Proposal to Public Health Agency of Canada (PHAC) Cancer Program - Public Health Community Programming for funding

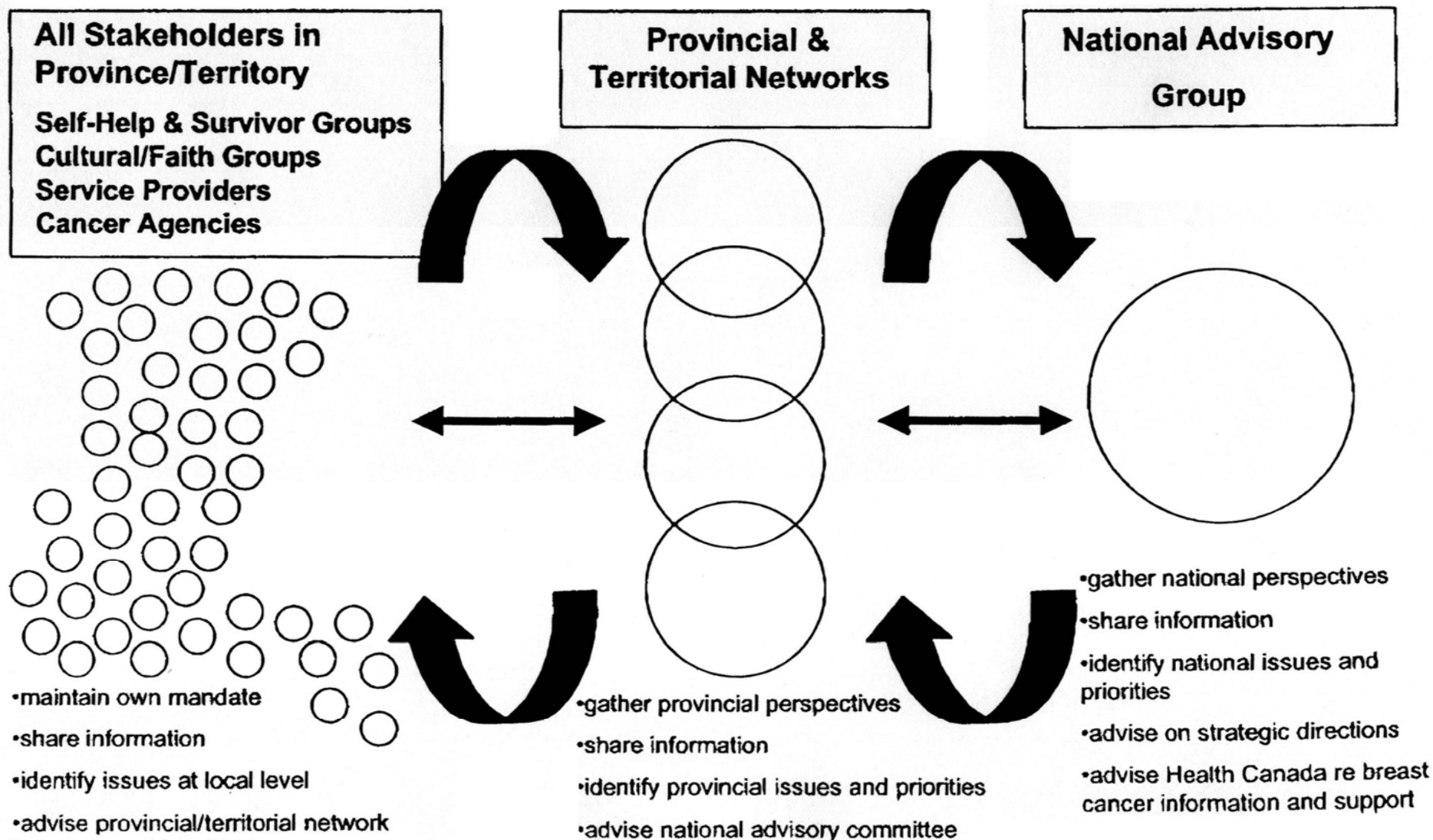
History



- **1993** National Forum on Breast Cancer
- **1993-1998** Canadian Breast Cancer Initiative established
 - National Breast Screening Program
 - Clinical Practice Guidelines
 - Breast Cancer Research Alliance
 - Education
 - Community Capacity Building
- **1999 - 2008** Canadian Breast Cancer Network and provincial / territorial networks funded by Canadian Breast Cancer Initiative – Community Capacity Component

Model for National Collaboration

Breast Cancer Information & Support



Community Capacity Building Committee

National Advisory Group



- One of five committees of the Canadian Breast Cancer Initiative established in 1998
- Each province and territory is represented
- Meet on average twice per year to exchange information, share resources and projects

Background of New Brunswick Breast Cancer Information Partnership

- Created in 1998 as a recommendation of the Atlantic Breast Cancer Information Partnership
- Incorporated in 2003
- Assessment, development and distribution of bilingual information kits for newly diagnosed patients
- From its formation, a member has represented NBBCIP at the national level - CCBC



NBBCIP Accomplishments

- Representation on National CBCI-CCB Committee
- Inter-Provincial/Territorial collaboration with other Networks
- Purple Violet Breast Cancer Information Kit
- National Resource for Advanced Breast Cancer
- Aboriginal Initiatives
- Annual Regional Awareness Events
- Sponsor delegates to attend Breast Cancer Events



**New Brunswick Breast Cancer
Information Partnership,
Inc./Partenariat d'information au
Nouveau-Brunswick sur le
cancer du sein, Inc.**

NBBCIP Challenges

- Concerns about volunteer burnout
- Lack of funding for administrative support
- Bilingual province
 - Expense of translation
 - Communication
- Geography
- Collaboration with Aboriginal Communities



NBBCIP Strategies Resulted in...

- Explored feasibility of collaboration with women's cancers (gynecological cancers: ovarian, cervical & uterine)
- Inter-Provincial/Territorial collaboration with other Breast and Women's Cancer Networks
 - Manitoba Breast & Women's Cancer Network
 - Expanded in October 2006
 - Utilize a regional representation/community contacts model
 - Funding from CancerCare Manitoba, PHAC, CBCF (Prairie), etc.
 - Very successful, evolving program
 - Willing to share their expertise

NBBCIP Collaboration with Atlantic Breast Cancer Networks

- Fall 2007 – NBBCIP approached the other Atlantic Breast Cancer Networks to discuss collaborating and expanding their work to include gynecological cancers
- Breast Cancer Network committee wanted more information and broader discussion; applied for funding
- A study of women's cancers in Atlantic Canada would identify statistics, needs and gaps

Collaboration led to...

Profile of Women's Cancers in Atlantic Canada

Where Do We Go From Here?

Support services for women with breast, cervical, ovarian and uterine cancer in Atlantic Canada

- Research by Atlantic Centre of Excellence for Women's Health
- Funded by the Canadian Partnership Against Cancer (CPAC)
- Research centered on incidence and mortality rates in Atlantic Canada and the support services in existence (who, what, where, why)

Profile of Women's Cancers in Atlantic Canada

- Collected cancer data from published reports and contact with provincial cancer agencies
- Environmental scan of support services
- Interviews and focus groups with cancer survivors in New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island

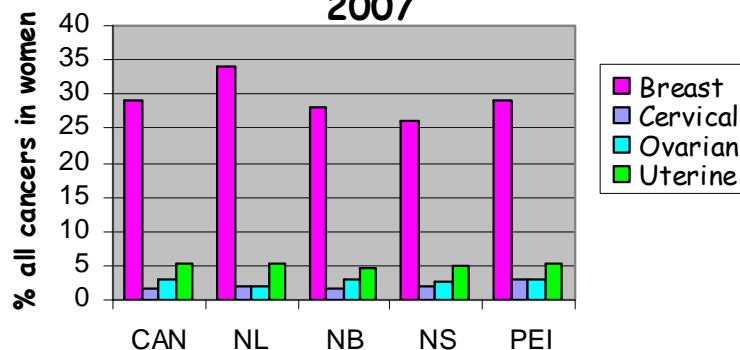
Profile of Women's Cancers in Atlantic Canada

- Significant gap between the # of breast cancer cases/deaths and the # of cervical, ovarian and uterine cancer cases/deaths
- Many generic cancer services and support - breast cancer programs are far more common than those for women with cervical, ovarian and uterine cancers
- Gaps in access; varied knowledge about services and support; available information not always complete, reliable, accessible or timely

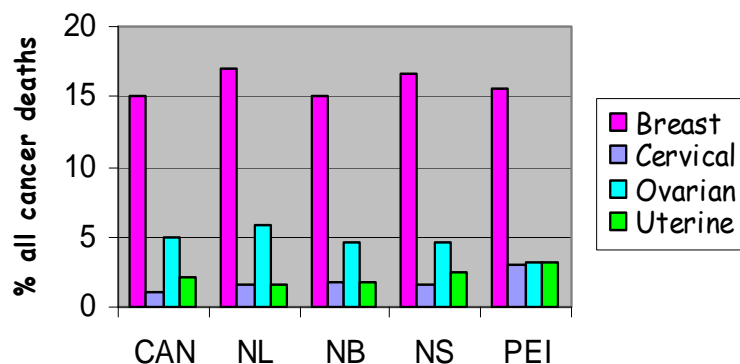
Profile of Women's Cancers in Atlantic Canada

Graphs by the Atlantic Centre of Excellence for Women's Health

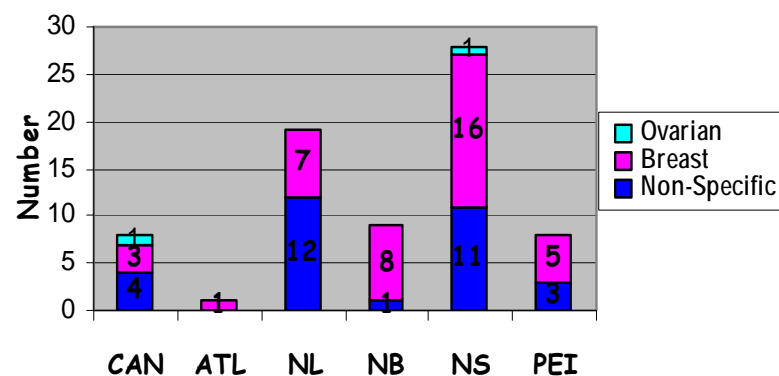
Incidence of 'Women's' Cancers, 2007



Mortality, 'Women's' Cancers, 2007



Cancer Support Services for Atlantic Canadians, 2007



Profile Conclusions & Recommendations

Many women living with cancer remain underserved.
More effort is needed to reach out.

- Encourage health care organizations – formal and informal – to ensure that the information they distribute is timely, accurate and reliable as well as available in a variety of formats
- Foster new research on the needs of women from vulnerable and disadvantaged communities who are faced with a diagnosis of cancer
- Promote the creation of publicly-funded cancer patient navigator programs throughout Atlantic Canada
- **Explore the possibility of adopting and adapting the processes and products developed by breast cancer support networks in Atlantic Canada to meet the needs of those with other women's cancers**

The profile led to...

The Atlantic Invitational Think Tank on Women's Cancers

March 31, 2008

- The first consultation of its kind in Atlantic Canada
- NBBCIP Inc. received funding from PHAC
- Organized in collaboration with the other Atlantic Breast Cancer Networks (NL, NS, PEI)
- Facilitation, event planning and report writing by THE **Quaich** INC.



Purpose of Think Tank

- Profile women's cancers in Atlantic Canada
- Explore strategies to assist people affected by women's cancers
- Explore the potential relevance of breast cancer information and support initiatives to other cancers
- Identify strategies to partner/collaborate

Think Tank Invitees

- Health professionals, community agencies, policy makers, volunteers and people affected by women's cancers





The Think Tank led to...

- ... further exploration of the concept of partnering to address women's cancers in the region
- ...circulation of the meeting report to attendees' organizations; report feedback on organizations' response

Think Tank Evaluation

- Evaluation report
 - **95%** - the work was a **good first step** toward expanding capacity to address women's cancers in Atlantic Canada
 - **95%** - Think Tank was successful in helping determine ways to **benefit provincially by building on the experiences of the breast cancer partnerships**
 - Decision-makers/policy makers found the report informative and would **like to see the work move forward**
 - **91%** - support for having the **Provincial Breast Cancer Information Partnerships/Networks** take the lead



NB & NL have
expanded their
Networks to
include women's
cancers



NBBCIP Lessons Learned

Lessons learned from the Breast Cancer experience that we want to bring to a Women's Cancer Network:

- Share Best Practices
- Maximize Utilization of Resources
- Choose projects carefully
- Build on Existing Structures and Processes (Capacity)



NBBCIP Expansion

- May 2008 - NBBCIP Inc. voted to integrate women's cancers into the partnership
- September 2008 - First provincial meeting of expanded network; elected interim executive with representation from all stakeholders
- Work underway to revise incorporation status

NB Women's Cancer Network

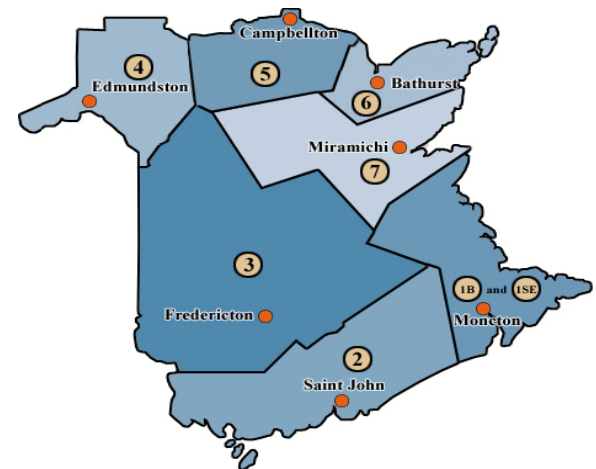
Why Expand?

- Breast cancer patient navigators identified a need to expand the network
- Expansion was a key recommendation of the profile
- Think Tank attendees supported having the Breast Cancer Networks establish a coalition to include women's cancers in each province
- NBBCIP September 2008 meeting included key players from the women's cancer community. Positive response; strategies for moving forward. New members, organizational support and renewed vitality.

New Membership

- New members from health and community agencies with an interest in women's cancers:
 - Canadian Cancer Society
 - New Brunswick Public Library Services
 - New Brunswick Cancer Network
 - Hospice Greater Saint John
 - Ovarian Cancer Canada – Atlantic Division
 - Breast & Cervical Screening Program
 - New Brunswick Advisory Council on the Status of Women
- Strong relationships with the Atlantic Centre of Excellence for Women's Health and The Quaich Inc.
- Funding for breast cancer kit contents provided by the Canadian Breast Cancer Foundation - Atlantic

The expansion of the New Brunswick Network to include gynecological cancers led to...



Proposal to PHAC

Cancer Program - Public Health Community Programming

An Integration Model of Women's Cancers into the NBBCIP Inc. within a Bilingual Framework

- Submitted for added financial resources to integrate women's cancers into the breast cancer model
- Want to create the country's first Women's Cancers Community Capacity Building Model within a bilingual framework
- This model could be easily adapted, in whole or in part, by other networks across the country to reach linguistically or culturally diverse populations
- Will serve a larger population by increasing the focus on underserved groups and be willingly shared throughout social programming

NB Women's Cancer Network

Links with other Networks

- Building upon the work of the Manitoba Breast and Women's Cancer Network
- Plans to collaborate with NL Breast and Women's Cancer Network





NB Women's Cancer Network

Objectives

1. Create an integrated approach to cancer support and management to meet the needs of women diagnosed with breast and other cancers
2. Develop a delivery model for integrating women's cancers (gynecological cancers – cervical, ovarian and uterine) into the provincial breast cancer network
3. Expand the existing breast cancer network to extend the availability of resources, networking and support to underserved groups: women with gynecological cancers, rural communities, and French communities in New Brunswick

NB Women's Cancer Network

Status of proposal

- Proposal is under consideration by PHAC, and has moved through several levels of the approval process
- Work is underway despite not knowing funding status. NB Network will continue with expansion, but will have to revise timelines and objectives if funding is not received



Research & Public Policy

- Discussion and **collaboration** among breast cancer Networks led to...
- **Research**
 - The profile of women's cancers identified a need: women's cancers are underserved. This led to...
- **Public Policy**
 - Representation from government, health professionals and NGOs at the Think Tank and in Network membership
 - To date, NL & NB have expanded their networks to include women's cancers

Conclusion

- NB Network expansion is innovative, flowing from the research profile recommendations and the collaborative work at the Think Tank
- Respecting lessons learned, NB intends to create a model based on its experience in a bilingual, largely rural population with limited resources
- The new Network will enhance the availability of resources in the province, extend capacity for support to a wider community, and serve as a model for other locations and organizations



Questions?