Overview
To make informed decisions about breast cancer, women need access to the right information, in a helpful format, and at the time it is needed. Women have become more outspoken about the inadequacies surrounding the availability and access to breast cancer information. Their efforts have led to an increased emphasis on information provision about breast cancer in Canada during the past several years.

In response to the identified inadequacies surrounding access to information about breast cancer, Health Canada launched the Breast Cancer Information Exchange Pilot Projects (BCIEPPs) in 1993. *Breast Cancer InfoLink, Prairies/NWT* was one of five federally funded 5-year regional projects established to increase access and availability of breast cancer information.

The prime objective of the pilot project was to assist persons living with breast cancer and their families, caregivers, and those at risk of contracting breast cancer in making informed decisions about a variety of concerns related to breast cancer. A secondary objective was to encourage partnerships among those involved in the collection and dissemination of breast cancer information.

Some of the key activities initiated through Breast Cancer InfoLink included planning and implementing participatory needs assessments for several populations (e.g., aboriginal women, rural physicians, women at risk), a Community Contact Program, production and printing of Breast Cancer InfoLink resources, videos, information resource kit, aboriginal education package and outreach presentations.

Lessons Learned from the Project
As the fifth year of the project unfolded, it was important to review the progress that has been made and to identify lessons that have been learned thus far. This was achieved through a series of program reviews. External evaluators conducted two process evaluations. These evaluations were augmented by two internal process reviews.

Several important lessons have been learned through the Breast Cancer InfoLink project. Overall, people were generally very positive about their involvement in the project. Most informants felt that the project’s objectives were appropriate, but recommended that more focus be placed on the delivery of breast cancer information to women in rural and remote areas and also to currently healthy women.

There were several comments that the regionalization of the project was no longer a valid structure, although important at the inception of the initiative. It was suggested that Breast Cancer InfoLink should reorganize to become more community-based and provincial in scope. A coalition model in which partners are truly accountable and contribute to the maintenance and enhancement of the program was also suggested.

Important linkages have been made with organizations and agencies to facilitate the success of the project. However, it was also acknowledged that ongoing work was required to identify other partnerships that would facilitate the activities of Breast Cancer InfoLink. In particular, more and stronger partnerships were needed at the provincial (e.g., cancer centres) and community levels.

The feedback suggested strong satisfaction with the products emanating from Breast Cancer InfoLink, and the way in which it has responded to the needs of breast cancer survivors. The direct involvement of breast cancer survivors and organizations representing survivors has been integral to the accomplishments of the project.

Recommendations were made to establish stronger ties with health care professionals and their respective professional associations (e.g., College of Family Physicians) who interact with breast cancer patients. It was also recommended that the project strive for better integration with breast/health preventative programs, such as those offered by voluntary cancer organizations and women’s health centres.

All reviews concluded that the pilot phase (5 years) was too short given the complexity of the project and the amount of preparation needed to lay the foundation for its initiatives. The work accomplished to date has only scratched the surface of breast cancer patients’ needs and while other information needs have been identified, the work to meet them has not yet begun. In order to further this work, Breast Cancer InfoLink has moved towards a provincial focus, with funding support from the Alberta Cancer Board. Much of its future work will focus on provincial and community-based initiatives.

*Monica Schwann, BA, MCS*  
*Coordinator, Breast Cancer InfoLink*

References