

OBCEP PUBLICATION POLICIES AND PROCEDURES

The Ontario Breast Cancer Exchange Partnership (OBCEP) is a coalition of organizations committed to ensuring that information about breast cancer is available to all people in Ontario. As a coalition, the OBCEP brings together many members of Ontario's breast cancer community and provides a forum for information sharing, cooperative, coordinated problem-solving and action concerning issues related to breast cancer information. Together, its members work to improve access to information about breast cancer for women, their families, and health care professionals. This document outlines OBCEP's publication policies.

POLICIES

I GENERAL PUBLICATION

The OBCEP defines its role as identifying gaps in breast cancer information, stimulating activity to fill those gaps, and facilitating publication through pre-existing channels with other partners—it is not a primary provider of information to the public. OBCEP will consider information needs across the spectrum of prevention, screening, early diagnosis, treatment, and follow-up care including survivorship and palliative care. OBCEP may address conventional and alternative therapies, publications in languages other than English, and formats specific to cultural preferences.

Where an information need is demonstrated the OBCEP may pursue publication opportunities with other partners and retain the option to publish in any format on its own if partners and/or co-sponsors cannot be found. Publication projects may be proposed both by the OBCEP and/or its partners and external parties. Proposed publication projects will be reviewed using the criteria below.

Is the information new?

If Yes:

- Is the information factual and credible?
- Is the information available commonly understandable? (e.g. highly technical or medical language versus accepted reading level)
- Is the information available accessible? (e.g., format, availability)
- Is the information and format appropriate for its intended audience? (e.g. USA or national in scope versus regional or local;)
- Is there an audience (and how large an audience) for the information?
- What is (are) the credentials of the author(s)?

If No:

- What other sources of information are available on the topic?
- How recently have existing resources been updated? Is the existing information factual and credible?
- What does the proposed resource add to the existing information?
- Is the existing information available commonly understandable? (e.g. highly technical or medical language versus accepted reading level)
- Is the existing information available accessible? (e.g., format, availability)
- Is the existing information and format appropriate for its intended audience? (e.g. USA or national in scope versus regional or local;)

- Is there an audience (and how large an audience) for the information?
- *What is (are) the credentials of the author(s)?*

II PUBLICATION ON PUBLIC WEB SITE

1. The OBCEP web site is provided as service to those seeking resources on breast cancer information and support in Ontario.
2. Through the site the public can learn about the OBCEP and its activities, as well as what others are doing to improve access to breast cancer information resources.
3. OBCEP's focus is provincial and it provides information or links to other reliable breast cancer information and support resources.
4. Community bulletin boards where people are invited to exchange information about breast cancer information activities, programs, and materials are also part of the web site.

OBCEP will consider posting an information resource on breast cancer and support where the resource:

- is reviewed and approved by the OBCEP Operations Group;
- increases knowledge;
- provides a service;
- poses no technical difficulties to post;
- author(s) provide the information free of charge and agree to editing for content or length if required by OBCEP; and,
- author(s) agree to update material or if this is not possible agree that OBCEP will remove the document from the site with a year or whenever deemed appropriate.

Examples of resources include local directories of supportive care services, fact sheets or information on specific aspects of treatment or support not easily available from other sources, and bibliographies or list of resources.

OBCEP information on the site includes:

Breast Cancer Information

- the OBCEP Fact Sheet Series (Hormone Replacement Therapy for Breast Cancer Survivors, Tamoxifen, Treatment-Induced Menopause)
- *Benign Breast Disease*
- *Ductal Carcinoma in Situ*

Breast Cancer Support Information

- Names and, where provided, telephone numbers for contact people in local support groups throughout the province;
- Phone numbers and web site links to the Canadian Cancer Society Reach to Recovery and other help lines and Willow Breast Cancer Support and Resource Services; and,

- Other support services throughout the province provided through links to regional or local breast cancer support groups and organizations.

OBCEP Business Activity

- OBCEP newsletter *Breast Cancer Info Exchange*
- Reports on OBCEP projects, events
- Reports on projects funded by Health Canada through the Community Capacity Component of the Population Health Fund
- Approved minutes of the OBCEP Operations Group Meetings

The site includes information on browsing health care sites on the web and news submitted by Coalition and Corresponding Members on projects and upcoming events.

Links to Other Breast Health Sites

Links to other Canadian and international web sites are provided on the OBCEP web site as a resource to browsers. To be linked sites must:

- Specifically be related to breast cancer or cancer
- Approved by the OBCEP Operations Group
- Meets Canadian Health Network criteria for evaluating health information on the web and the HON Code (see below)

Canadian Health Network Web Site Checklist

OBCEP uses the Canadian Health Network (CHN) checklist developed for evaluating the most trustworthy health information web sites. The CHN criteria is available online at: <http://www.canadian-health-network.ca/html/help/checklist1.html>.

1. Is the resource credible?
 - Is the author's name (or the name of the organization responsible for the document) clearly stated?
 - If the author is identified, is he or she a professional or accredited authority on the subject?
 - If not, does the author state his/her perspective on the subject (for example, by saying "I'm a cancer survivor," or "I've used chiropractors for 10 years")?
 - If an organization is responsible for the information, is it a reputable organization recognized as an authority on the subject?
 - If medical information is given by a non-professional, is this clearly said?
 - What kinds of evidence are provided to endorse a specific treatment or service? (Keep in mind that scientific studies and research have a different credibility than first-hand experience.)
 - Does the site provide contact information about the author (for example, full name, address, phone number, e-mail address)?
2. Is the content suitable?
 - Does the content discuss the issue(s) you're interested in?
 - Is there enough detail or does the information seem superficial?
 - Does the site have original content or does it only link to other sites?

3. Is the information relevant to you?
 - Does it match what you are looking for?
 - Is the information presented within a Canadian context?
4. Is the resource timely?
 - Is the information reviewed and/or updated often enough given the content? (For example, if it deals with the latest in safety features on child car seats, has it been changed lately?)
 - Is the date of the last update clearly marked on each item or screen?
 - If information is only valid for a short time, is this fact clearly labelled?
5. Is there clear and adequate disclosure?
 - Is the author's interest and/or mandate in developing and sharing this information clear (for example, a non-profit organization trying to promote exercise and active living or a fitness product company trying to sell you exercise equipment)?
 - Is there potential for bias or conflict of interest (for example, a company telling you that only their product or service is valuable)?
 - Are both (or all) sides of the issue presented?
 - If not, does the resource state that it presents only one side of an issue? (For example, an anti-abortion site should make its politics clear and not present itself as a family planning site.)
 - Are commercial links and/or sponsorships clearly stated?
 - Are these sponsorships separate from the health information content?
 - If the site collects or requests information about you, do they tell you exactly why they want this information?
 - Are their privacy guidelines stated?
 - If you have to register to use the site, is the reason clear and your privacy ensured?
6. Are there clear caution statements?
 - Does the site offer a clear statement that health information should not be taken as health advice or a substitute for visiting a health professional?
 - If there are fees associated with use of the resources on the site, are they clearly explained?
7. Is the site user-friendly?
 - Is the information presented in a clear manner?
 - Can you contact the author/administrator by e-mail if you have difficulties using the site?

The OBCEP web site also complies with the HON code developed by the Health on the Net Foundation and its main principles (from HON's web site at www.hon.ch/HONcode/Conduct.html).

1. **Authority**
Any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organization.
2. **Complementarity**
The information provided on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician.
3. **Confidentiality**
Confidentiality of data relating to individual patients and visitors to a medical/health Web site including their identity, is respected by this Web site. The Web site owners undertake to honour or exceed the legal requirements of medical/health information privacy that apply in the country or state where the Web site and mirror sites are located.
4. **Attribution**
Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page).
5. **Justifiability**
Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.
6. **Transparency of authorship**
The designers of this Web site will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her e-mail address clearly throughout the Web site.
7. **Transparency of sponsorship**
Support for this Web site will be clearly identified, including the identities of commercial and non-commercial organizations that have contributed funding, services or material for the site.
8. **Honesty in advertising and editorial policy**
If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the Web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

Public Bulletin Boards

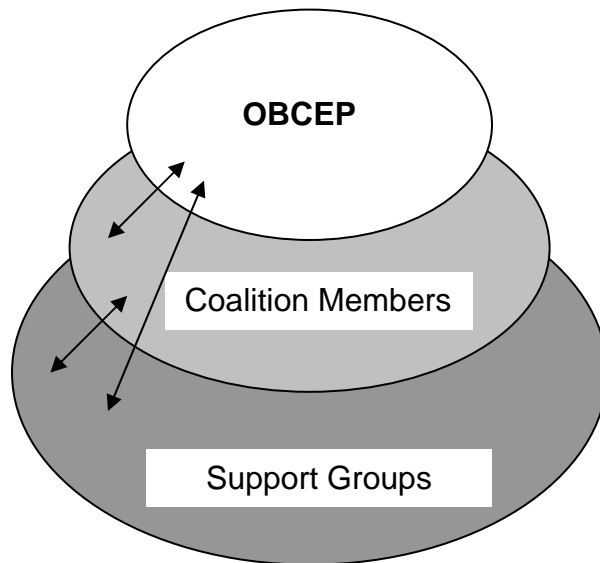
Three public bulletin boards provide a forum for members of the public to share information on resources, current activities and developing projects. The public bulletin boards are monitored regularly to ensure that the information is timely and appropriate, i.e., it is not intended as a marketing platform for individuals or companies selling products or services or for researchers or media producers to recruit study participants.

The OBCEP Operations Group will review requests from researchers on a case by case basis and media requests will be referred to the Canadian Cancer Society and/or Willow. Under no circumstances will the OBCEP release names of coalition or corresponding members to the media. The OBCEP Coordinator will monitor the bulletin boards regularly and any message deemed inappropriate will be removed.

III PUBLICATION ON PRIVATE SITE, OBCEP VIRTUAL COMMUNITY

Vision for the Virtual Community

The ultimate goal for a Virtual Community is to enhance the capacity of the stakeholder organizations to meet the needs for breast cancer information and support—it should help groups to do their work better.



The virtual community model builds on the existing context of Internet activity by breast cancer groups and adds value in terms of collaborative activity, access to information, and sharing of resources. The ultimate goal for a Virtual Community approach is to enhance the capacity of the stakeholder organizations to meet the needs for breast cancer information and support. Its purpose is to use technology as a tool that would enhance collaboration between and among a network of organization/groups with a stake in the provision of information about breast cancer and support for breast cancer survivors.

Objectives of the Virtual Community

- to enhance shared access to information about breast cancer;
- to enhance linkages and working relationships between and among local/regional, provincial/territorial, and national groups;
- to provide access to an inventory of all the players/stakeholders in the network;
- to facilitate the identification of issues and gaps;
- to facilitate sharing of ideas and concerns with others participating in network activities (committees/task groups);
- to facilitate the development of action plans; and,
- to hold meetings "on-line" and so decrease costs associated with frequent face-to-face meetings.

The model for the virtual community makes use of a web-based technology and various tools and is based on the assumption that a network exists composed of organizations with a stake in breast cancer information and support working together.

The private site, the "virtual community" of the site provides a forum for coalition, corresponding and other support and information groups to share information and experiences to help them do their work. The information that could include:

- Regional/local needs assessments
- Development of strategic or special plans
- Procedure for planning special events
- Minutes of planning meetings
- Other reports detailing challenges, disappointments, successes of group activity

While it is not intended that the OBCEP censor or restrict any Coalition or Corresponding Member partner from posting information to the Virtual Community, due to space limitations, propriety, and timeliness the OBCEP will exercise discretion in communication with network partners about posting information on the "private site".

Partner LinksCoalition of Stakeholders

The strategic direction for the OBCEP is set by its 36 coalition members. The coalition member groups are principally provincial or regional breast cancer groups that already sponsor their own web sites (see Table 1).

Corresponding Members

The Coalition Members work is complemented by over 70 "Corresponding Members" grassroots and breast cancer-survivor directed groups that do not have web sites but who have direct or indirect access to the internet and e-mail tools. The principal audience for the OBCEP virtual community is the grassroots organizations to enhance collaboration, information-sharing, and access to information. The key to linking these groups is to provide access to and training on the web and Internet-based tools.

Table 1. OBCEP Coalition Partner Web Sites

	Coalition Member Group	Web Site Address (URL)
1.	Bayview Support Network	www.tsrcc.on.ca/bsn/
2.	Breast Cancer Action Kingston	www.brcanactionkingston.com
3.	Breast Cancer Action Ottawa	www.bcaott.ca
4.	Breast Cancer Prevention Coalition	www.stopcancer.org
5.	Breast Cancer Research and Education Fund	people.becon.org/~bcancer
6.	Breast Cancer Support Services, Burlington	wchat.on.ca/web/bbcss
7.	Canadian Association of Nurses in Oncology	www.cos.ca/cano
8.	Canadian Breast Cancer Foundation	www.cbcf.org
9.	Canadian Breast Cancer Network	www.cbcn.ca
10.	Canadian Cancer Society	www.cancer.ca
11.	Cancer Care Ontario	www.cancercare.on.ca
12.	Cancer Information Service	www.cancer.ca
13.	Centre for Health Promotion	www.utoronto.ca/chp/
14.	Circle of Strength/Sudbury Breast Cancer Support Group	www.breastnorth.info
15.	College of Physicians and Surgeons of Ontario	www.cpsso.on.ca
16.	Connecting Rainbows	<i>Not N/A.</i>
17.	Hospice Association of Ontario	www.hospice.on.ca/
18.	Marvelle Koffler Breast Centre	www.mtsinai.on.ca/MKBC/
19.	Ministry of Health, Public Health Branch	www.gov.on.ca/health/
20.	Ministry of Health, Women's Health Council	www.womenshealthcouncil.com
21.	North York General Hospital Breast Diagnostic Centre	www.nygh.on.ca/gedicanc.htm
22.	Ontario Breast Screening Program	www.cancercare.on.ca/obsp
23.	Ontario College of Family Physicians	www.cfpc.ca/ocfp
24.	Ottawa Regional Women's Breast Health Centre	<i>Not N/A.</i>
25.	Peterborough Breast Cancer Support Group	<i>Not N/A.</i>
26.	Princess Margaret Hospital, University Health Network	www.ocipmh.org
27.	Sarnia Living With Breast Cancer	<i>Not N/A.</i>
28.	Sunnybrook & Women's Health Sciences Centre	www.sunnybrookandwomens.on.ca
29.	Supportive Cancer Care Research Unit, Hamilton	hiru.mcmaster.ca/scru/
30.	Thunder Bay Breast Health Coalition	<i>Not N/A.</i>
31.	Timmins Breast Screening Coalition	<i>Not N/A.</i>
32.	Toronto-Sunnybrook Regional Cancer Centre	www.tsrcc.on.ca
33.	Waterloo Region Breast Health Network	<i>Not N/A.</i>
34.	Wellspring	www.wellspring.ca
35.	Willow Breast Cancer Support & Resource Services	www.willow.org
36.	Wings Breast Cancer Support Group, Thornbury	<i>Not N/A.</i>