


CancerChatCanada

Reflections on a Pan-Canadian Support Initiative

CancerChatCanada Workshop
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cancerChat
CANADA

Professionally-led online support for Canadians affected by cancer

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“Thank God for this group! Everyone should be given the opportunity to join as it makes whole process of caring for your spouse easier.”

CancerChatCanada
Register on our secure website for upcoming groups.
[Click here](#)


Find out more about online support
The National Alliance for Psychosocial Support and Care is looking for professional psychosocial oncology counselors to facilitate online groups. If you think you got what it take or know somebody who does, click here to learn how.
[Join our email list](#)

What's New

October 9, 2012 / **Newsletters**
Psychosocial Oncology Newsletter Featuring a Couplelinks Story: One participant's perspectiv...
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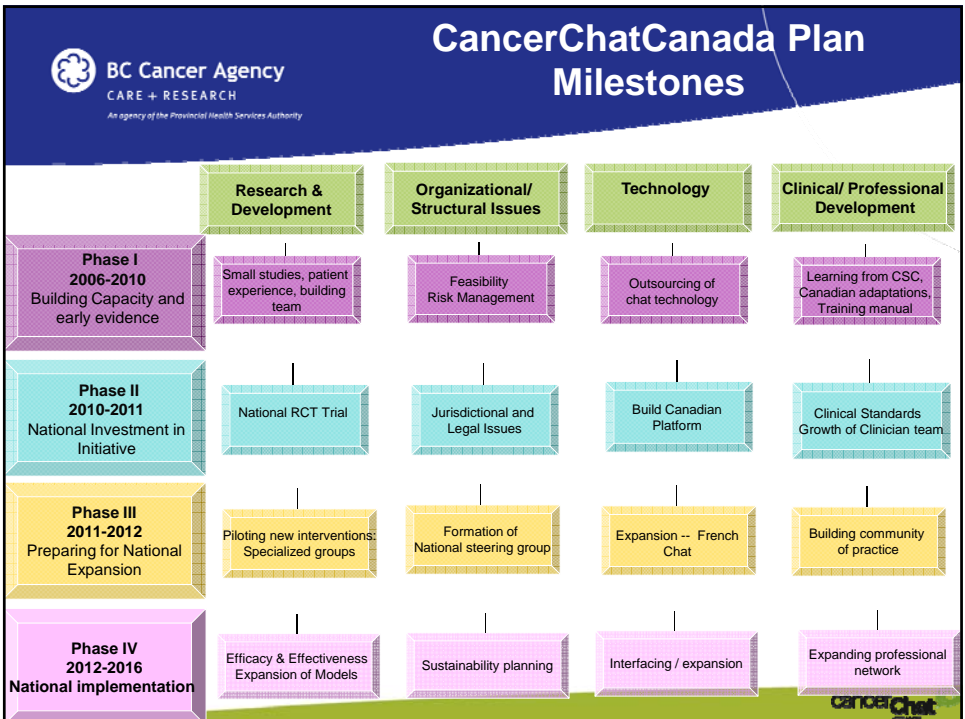
September 19, 2012 / **Group Schedules for Fall 2012**
Mixed Patient Group New online support group for ...

CancerchatCanada provides a safe place to connect with others facing similar challenges.
Click the play button to view the video



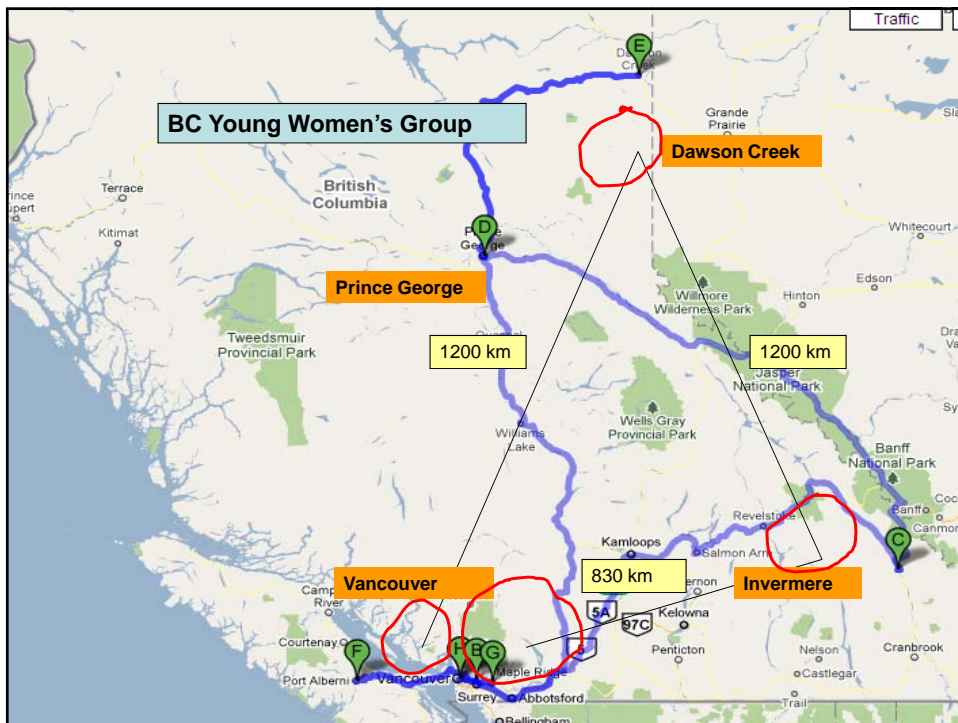
- **Vision of Canadian Strategy for Cancer Control**
 - Ethical imperative to innovate and collaborate
 - New focus on issue of inequality of access
 - Agenda to ‘Rebalance the focus’ of Canadian cancer care

- **Developing the Initiative**
 - 2006 Banff International Congress of Psychosocial Oncology
 - inspired by vision of technology to enable access
 - 2007-2009 meetings, workshops & formation of a national project team -- ‘integrated knowledge translation’
 - 2008-2012 phased plan involving concurrent streams of activity

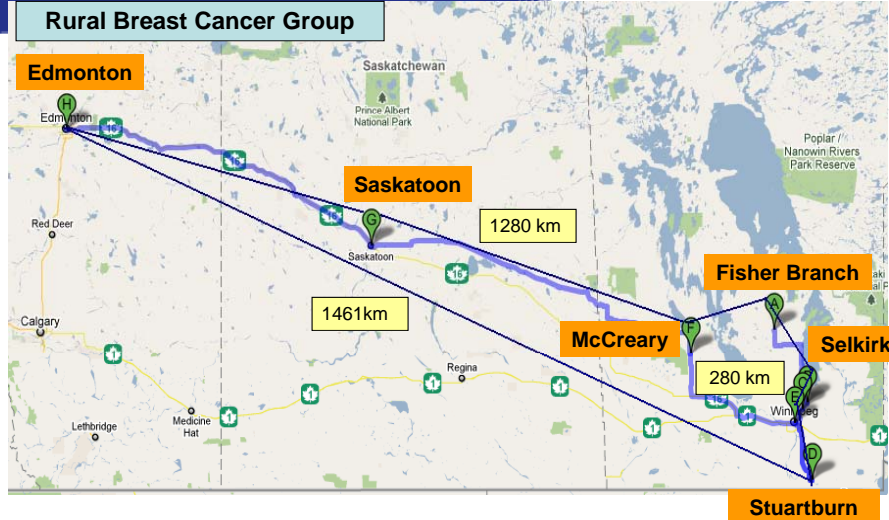


Where we are now (2013 Outcomes)

- **Pilot groups completed**
 - Mixed Diagnosis
 - Family Caregivers
 - Prostate, Head and Neck
 - Francophone Blood Cancer
 - Ovarian (with OCC)
 - Sexual Health (Gynecological)
- **RCT studies**
 - Young Breast Cancer Survivors
 - Rural Breast Cancer Survivors
 - National Young Breast Cancer Survivors
- **Coming soon**
 - OSG+Art therapy, YAC Film series+OSG
- **To-date, over 650 patients, survivors and family caregivers have received service, >100 (10 week) groups**



Rural Breast Cancer Group



CCC Outcomes

• **Underserved, moderate-to-highly distressed Canadians participate:**

- 45% with high school education
- 56% live outside large urban centers
- 32% with metastatic/advanced disease
- 23% too unwell to perform any work
- 86% no previous experience in a cancer support group

• **Attendance and drop out rates**

Over a 5 year period.....

- 1223 Canadians** registered to join a group:
 - **54%** screened and enrolled
 - **26%** declined or lost to follow-up
 - **20%** on active waitlist or referred elsewhere
- Weekly attendance **>70%**
- Completion rate is **77%**





Implementation & sustainability planning

- **15 organizations in 8 provinces within the CCC initiative**
 - 2 leadership groups
 - Regional leadership group for strategy and local implementation
 - Clinician scientist group overseeing practice standards, new intervention development
 - Community of practice
 - 19 facilitators engaged, online & offline peer supervision, act as local champions, participate in research
- **Favorable external evaluation and funding renewal to 2015**
 - Formalizing partnerships in intra-provincial agreements
 - Preparing business case, health authority buy-in



Research Outcomes

1. **Are pan-Canadian, professional-led OSG's feasible and acceptable? Can we reach targeted populations? Do they appear to satisfy and provide benefit?**
 - Evaluation of CancerChatCanada: A Program of Online Support for Canadians Affected by Cancer. 2013, *Current Oncology*, Vol 20 (1)
 - When jurisdictional boundaries become barriers to good patient care. 2013, *Current Oncology*, Vol 20 (1)
 - Professional positions on online psychosocial care in Canada: A review of current policy statements. *Canadian Journal of Community Mental Health (In press)*
2. **Can professionally-facilitated, live chat OSG's reduce distress and enhance adjustment & adaptation?**
 - **For whom, and when in the cancer trajectory?**
 - Benefits and Outcomes of an Internet-Based Psychosocial Intervention for Family Caregivers of Cancer Patients, *Supportive Care in Cancer (Submitted)*; Randomized Control Study Comparing Efficacy of Two Forms of Supported Self-Management for Young Breast Cancer Survivors (*In preparation*)
 - **What are the helpful group processes?**
 - Talking with Text: What Participants Value about Professionally-led Online Cancer Support Groups, *Social Science and Medicine, (Submitted)*
 - Facilitator Training Manual (with CSC, *unpublished manuscript*)





Processes

- Professionally-led live chat groups facilitate emotional expression and empowerment – professional facilitator is crucial
- Writing is therapeutic
 - *“by typing things out, it allowed us to get more out I think”*
 - *“It was easier because it was online... I can still type if I’m crying”*
- Privacy, semi-anonymity and live chat each contribute to group bonding & emotional expression
 - **Benign disinhibition – genuineness, vulnerability, warmth**
 - **Hyper-personal communication – positive projections**
 - **Heightened focus on communication task - intensity**

“The anonymity of being online helped me talk about private things-it was liberating.”



Implementation Lessons Learned

- Research is the easy part -- implementing innovation within health system requires extraordinary patience & tenacity, new skills
- RCT evidence neither necessary nor sufficient for moving service forward – patient stories have been compelling
- Continuity and communication critical for partners as well as patients – relationships inspire intention, action & commitment
- Managers/leaders are unexpected champions who found opportunity and solutions despite current, difficult health care climate
- Jurisdictional and regional allegiances/issues/politics continue to be challenges – but to date, not insurmountable (power of the ethical, super-ordinate goal)

