

# Workshop Report

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## “Sustaining our Community for Knowledge Exchange and Capacity Building in Psychosocial Cancer Care”

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Lynne Robinson, PhD, RPsych  
Rob Rutledge, MD, FRCPC

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## **EXECUTIVE SUMMARY**

This workshop was attended by 31 stakeholders with backgrounds in psychosocial cancer care including health care professionals, health researchers, and representatives from Canadian cancer Community Based Organizations (CBOs). The major goals of the workshop were to foster ongoing working relationships between attendees and develop a sustainability plan for a community of practice dedicated to providing high-quality psychosocial support for all Canadians affected by cancer. The workshop focused on the primary task arising out of the 2008 workshop, which was to develop a portal/clearinghouse to facilitate information-sharing amongst these stakeholders.

The group carried out a self-evaluation which identified various levels of involvement but with everyone feeling included and part of the process. The biggest challenge was the small working group, the constant addition of new members and the speed of the progress, which makes it hard for everyone to keep track of events. We identified a need to develop better strategies to keep everyone 'in the loop'. The guest speaker identified strategies that successful communities of practice use and we broke into small groups to come up with suggestions for developing the new CPOPonline website. Many suggestions were offered, providing guidance for the website for several years to come as they are implemented. Finally, the workshop itself was evaluated. On a scale of 1-7, with 7 the highest, participants rated the workshop at 5 or above on all measures.

## **BACKGROUND**

### **Why CPOP?**

While each person's cancer journey is individual <sup>1</sup>, the diagnosis and treatment of cancer can be stressful events capable of profound and far-reaching effects. Distress is common and can be high, and even disabling, with effects continuing well beyond diagnosis and treatment <sup>1</sup>. Not only must individuals deal with the physical effects of the illness and its treatment, but also with any resulting emotional, spiritual, psychological, and social effects. Beyond the requirement for medical care, attention to psychosocial needs such as reassurance, a sense of comfort and personal control, positive self-esteem, the ability to cope, finding meaning and purpose in life, and information to assist decision-making and to help quell confusion, anxiety and fear<sup>1</sup> is required.

Increasing recognition is being paid to this aspect of care. There is budding evidence for the relationship between psychosocial interventions and enhanced quality of life, and increased survival potential <sup>1</sup>. Meeting the medical needs of cancer patients is essential. However, the psychosocial needs of both patients and their supporters often are not addressed by the conventional medical system, and conversely are increasingly recognized and frequently met by CBOs. There is little published information on how psychosocial needs are being met and limited means to share information among the following "pillars" of psychosocial care: CAPO/psychosocial health professionals, researchers, CBOs, and the conventional medical system. Increasingly, all stakeholders are recognizing the need to work together to provide seamless, integrated psychosocial cancer care to those who need it.

Since 2006 members of CPOP have been meeting annually as an adjunct to the CAPO conference to develop objectives for the coming year, plan to achieve those objectives and discuss achievements of the previous year. Each year we invite one or more keynote speakers on the major topic of the Workshop and receive the Report on the previous year's Workshop. Reports from all four years to date, as well as other CPOP materials can be found archived on the CPOPonline website, available through [cancerview.ca](http://cancerview.ca)

### **Project History**

#### **2006**

This project developed out of a meeting held during the 2006 annual CAPO conference. At this meeting, representatives from 11 CBOs met with CAPO representatives to discuss how CAPO could support them. The consensus from this first meeting was the need to develop:

- 1) mechanisms to share information (electronic resources, workshops and training sessions)
- 2) processes for research collaboration and knowledge translation (e.g.: implementing research findings on a practical level)
- 3) consistent standards (e.g.: reviewing and approving educational materials, developing a standardized curriculum for volunteers)

## 2007

The first step in meeting the needs identified in 2006 was to carry out a study of the knowledge exchange (KE) practices and barriers to KE within Canadian psychosocial cancer CBOs. Findings from this survey were reported at the workshop in Winnipeg in May 2007 and the report is archived at CPOPonline. Overall, the participants in this workshop clearly identified a need for a partnership that would link all those providing psychosocial cancer care in a variety of ways. The partnership would have a clear structure, with a vision and a set of achievable goals. It would be allied with the Canadian Association of Psychosocial Oncology (CAPO) and would accomplish two broad goals:

- 1) it would support partners in developing the best possible Knowledge Exchange (KE) strategies and
- 2) those KE strategies would open channels for streamlining of services to survivors and their family members, for sharing expertise in the delivery of programs, and for mutual involvement in research. The project would itself include an evaluation and a strategy for sharing findings beyond the partners.

Early in the 2007 workshop, participants were asked to consider developing a new name for the knowledge exchange project. Suggestions were posted and a vote confirmed our name to be: ***“Canadian Psychosocial Oncology Partners” (CPOP).***

A community of practice (CoP) model seemed to best fill the gaps identified in 2006 and 2007.

## 2008

In 2008, Lynne and co-PI Mary Jane Esplen received funding to develop the online Community of Practice identified as a goal in the 2007 Workshop. Thirty-three members of the CPOP group met in Halifax, Nova Scotia to further develop the vision of seamless integrated care and to explore what we wanted in an online CoP in psychosocial oncology. At the 2008 workshop, CPOP members identified:

- a. The resources participants had to offer an online psychosocial oncology CoP
- b. The resources participants wanted/needed from an online psychosocial oncology CoP
- c. The factors that would keep participants and their organizations involved in a CoP
- d. Effective communication tools for the community
- e. Barriers and gaps the community needed to overcome in developing a CoP
- f. Specific functions participants want to see in the website

## **THE 2009 WORKSHOP**

The aims of the 2009 workshop were to:

- Bring together key stakeholder groups in psychosocial cancer care to further develop the vision of seamless integrated care and to foster ongoing working relationships amongst members
- Develop a sense of how to market the online psychosocial oncology CoP
- Develop a sustainability plan for the online community of practice for collaboration and information sharing by:
  - a. Evaluating the effectiveness of the CPOP project to develop and implement the community of practice (both online and in workshops)
  - b. Understanding the challenges and successes of the project from a member perspective
  - c. Developing a sustainable action plan for what individual members and their organizations can do to ensure success of the project. This included discussions around:
    - i. discussion forums on the website
    - ii. the format and interactive components of the repository
    - iii. creating documents using the wiki function
    - iv. submitting to the news/member highlights component of the site

### **PARTICIPANTS:**

The event was attended by 31 key participants with backgrounds in psychosocial cancer care including health care professionals, health researchers, and representatives from Canadian cancer CBOs.

### **ACTIVITIES:**

The workshop began on Saturday evening with a networking dinner. Lynne & Rob as usual provided an overview of the history of the project and backgrounders related to knowledge exchange and communities of practice, as well as a review of the website pages and the various functions it offers. Short talks were also given by project partners from CPAC, CAPO, and the Canadian Cancer Society to “set the stage” for the work to be done.

#### **Self evaluation of CPOP**

For the first hour, members broke into several focus groups to provide feedback on how our community is functioning. They were asked to:

1. Describe how they were involved in the development and implementation of the community of practice
2. Describe their satisfaction with their level of involvement
3. Discuss the challenges they saw during the process and if/how these challenges were overcome
4. Describe what they saw as the greatest successes of the project

## 5. Provide feedback on the functionality and design of the website

### *Level of Involvement*

When participants were asked to share their involvement with the development and implementation of the CoP, they referred to their professional roles as community-based organization leaders, CPOP organizers, CAPO leaders, researchers and practitioners. Some had just started working with the CoP while others had been involved since the inception of the project. There were also various levels of involvement. Some participants had to limit their level of engagement due to their professional role, while others had been engaged and committed from the outset.

### *Satisfaction with Involvement*

There were also a range of views on satisfaction with the level of involvement. Some participants admitted to feeling “around the periphery” of the project and others had difficulty keeping track of CPOP’s momentum. Many participants were, however, satisfied with their level of involvement and felt that the communications helped them keep in touch with what was going on. A number of participants mentioned that they were excited to increase their involvement with the community as it prepared to “go online” through the internet. Another comment that came up across most of the groups was that participants were satisfied with the inclusiveness of the group – several new members mentioned that they felt welcome despite not having been involved in the past.

### *Challenges in the Process*

Not surprisingly, members identified a number of challenges.

The biggest one identified was the small working group and the rapid pace of activity. Members commented that this has the advantage that it enabled the group to quickly move forward – but made it hard to act on new opportunities, and for members to keep track and to feel involved. Members felt perhaps the group should be expanded to be more inclusive in the future (i.e. representation from western provinces). They felt it was important to get buy-in and continuing investment from key players and to continue to foster relationships outside of the CPOP workshop – during the year. Members identified the need for a personal draw (i.e. teleconferences to keep people in the loop and engaged) and more communications; everyone needs to know more about what’s going on. Members also identified a need for more consistency in who comes to our CPOP meetings and for collecting more information from hospitals.

Members identified that there is still some confusion around CPOP’s mandate/mission and a need for clarity on it. Participants wondered “Are WE the CoP, or are we the facilitators for CoP? Does the CoP exist now?”

Another issue was “finding the balance between relevancy to ME and inundation of information”. As one group noted “We are busy – it can be difficult to find time”

Some additional issues were raised;

- ✓ Intellectual property rights

- ✓ Sustainability – who’s going to support this long term?
- ✓ Lack of continuity – will the website help us? Will this work?
- ✓ Need for a system that is wisdom-based and knowledge-informed
- ✓ Focus groups took place too early – were still trying to form thoughts

### *Our Greatest Successes*

The group felt that we had great success in growing new and important connections, building relationships and creating a network with a diverse range of participants. Another area of strength the group identified was real involvement of members in the development process of the community. We identified “Real consultation – not just lip service” as a plus. Another comment was “We feel invested – we got to name this, feel we’ve been a part of it and have been fundamentally involved in what the final product looks like”.

Finally, the fact that we got funding to build CPOPonline and run the workshops was seen as a “HUGE gain”.

### *Final Thoughts on the Website*

Members were “Excited about the potential as a portal for everyone involved in cancer journey” while others were “Not sure yet – what it will look like, how things will function”. There was a sense that the site “Looks workable” and that the “Logo pulls it together”. Participants identified a number of needs: a code of ethics, a way of dealing with intellectual property rights, an examination of how it will add value to cancer agencies, a balance between enough information and inundating people (i.e. with email updates), as well as an ongoing need for “opportunities to interact with real people in real time”.

## **Keynote speech**

Dr. Allan Best from the University of British Columbia gave our keynote speech. His talk focused on developing and sustaining a community of practice (CoP), and how CoPs function. He used the National Cancer Institute of Canada’s framework for knowledge integration as an example of how CoPs differ from other approaches, and shared success stories and lessons learned to guide the group in developing a sustainable model in psychosocial cancer in Canada. The slides from his talk are available on CPOPonline.

## **Planning for the Website**

To meet the objective of planning for sustainability of the online space, we broke into small groups to plan for what we would like to have on the site. Each group addressed one of the four major functions we wanted to have.

### *1. Discussion Board*

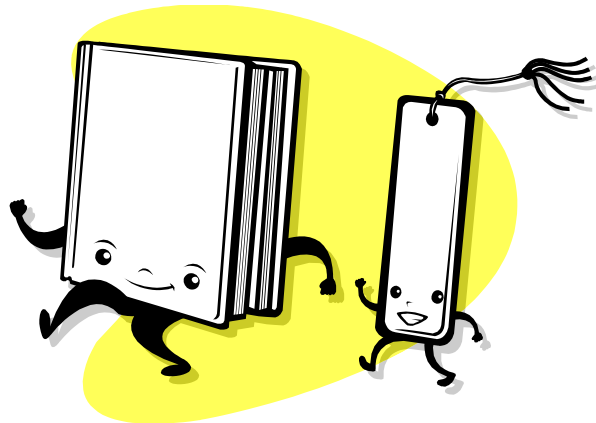
Some of the key issues raised were the benefits of having topic specific email notification on new postings, ability to search by keywords, the need for F.A.Qs. Questions were raised about who would moderate the board and/or be responsible for summarizing a thread. The need to develop an etiquette for these boards including the need for posters to use words that make it easy to search for and find the post. We agreed on the need to create ‘teaser items’ or items by key personel such as: → hot issues → Mike Fluit on brain tumor → Steve Simpson → MaryJane

Esplen → Jill Taylor-Brown. The suggestion was that Anthony Laycock be asked to engage the CAPO board in this.

## 2. *Virtual Library*

Users wanted:

- ✓ some system of rating materials in the library, such as a system of stars or reviews or even personal feedback, possibly with several options.
- ✓ some principles for what would be in the library
- ✓ a summary of documents; users felt this might, in future, be done by a review committee or by one dedicated person.
- ✓ links to journal articles
- ✓ useful forms that could be adapted to other uses (e.g. program evaluation frameworks; consents for service delivery, research or evaluation)
- ✓ linguistically/culturally appropriate resources
- ✓ ways to move discussions or wiki documents into the library once completed.
- ✓ some way to actually share hard copies of research articles, it was felt that directors could use the repository to order articles which could then be shared with members



Globalink, a tobacco control site was offered as an example of a useful repository

Concerns were raised about negative reviews, copyright issues (perhaps handled by linking to materials).

## 3. *Discussion forum & News and highlights*

In this group, members felt we needed an area for researchers to post requests for participants in research studies and for calls for proposals for research funding. They identified a need for the latest news in psychosocial cancer: the latest cancer statistics; the results of randomized controlled trials; new initiatives, “Hot off the press – research abstracts”, news releases from CBO’s and PDF’s of newsletters, e-news, job postings, etc. They wanted to have a calendar of public events and professional conferences and of calls for proposals for research funding. Members wanted both Canadian and international contributions and they wanted a way to archive a resume of discussion threads.



Members also raised several questions:

- Who should have access to this part of the site: professional only or public access?
- What should submission criteria be?
- Timelines for prompting postings

➤ Who is responsible for the frequency of contributions

Members suggested using RSS feeds (real simple syndication) and having a template for news (each type).

## Marketing CPOP and CPOPonline

We broke into smaller groups to discuss the marketing of CPOP and our website. We talked about who should be invited to be part of CPOP and how we would approach them. We came up with quite a few stakeholders to be invited (a number of those mentioned were already involved).

*Who should be invited:*

We identified many CBOs which are not yet well represented as part of CPOP: Alli's journey, Chasing Rainbows, Jason's fund in Quebec, Hope & Cope, GILDA'S CLUB, Hopespring, - Heorth Place, the Canadian Cancer Society, Myeloma Canada, the Leukemia & Lymphoma Society, Organisation Multiressources des Personnes Atteintes de Cancer (Ompac) - as well as CBOS representing testicular, prostate and lung cancer (LCC)

A number of professional organizations were identified: These included; members of CAPO, CBCN, CPEN (USA & CANADA), IPOS, APOS, CARO, CAMO, the Western Association of Clinical Associates, UPCON, Canadian Association of Nurses in Oncology (CANO); P.O.R.T. Fellowship program; the Canadian Evaluation Society and Virtual Hospice.

We also identified researchers and research organizations to connect with: Research institutes/networks; Palliative care networks and heads of teams; the Atlantic Cancer Research Network. We also wanted to connect with individual academic researchers and with students.

*How should we connect with new potential members?*

Brainstorming, we came up with many ways to connect with those who don't attend this workshop:

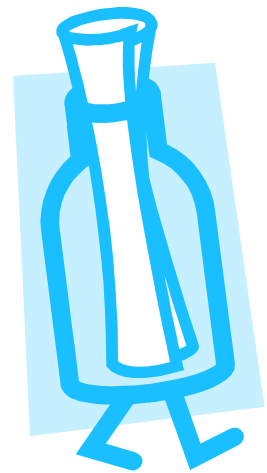
Members identified key strategies:

- ✓ framing our message to specific groups.
  - For researchers, key elements of this message were: opportunities for partnership, the idea of the CoP as a new phenomenon, CPOP as allowing access to important populations for research, opportunities to share, discuss and advertise research findings, linkages to other people and researchers, creating their own research profile, sharing their interests and availability for research partnerships. Researchers interested in community-based research could be targeted in particular.
- ✓ creating very positive messages
- ✓ identifying incentives for individuals "What's in it for me". Some examples of such incentives for a variety of users were noted:
  - Raising the Profile of an individual or group by posting news & highlights
  - Making the community aware of events created by users

- Creating an Agency Profile Page
- Getting the users' message out to a wider and/or different population
- Access to research, researchers, funding opportunities
- Opportunities to work with CBOs on realistic goals
- ✓ offering useful resources to users such as templates for creating useful tools, printable materials, examples of evaluation forms and consent forms, information for patients on important topics such as return to work and risk management, a job board, information for members on how to network, find partners for various situations, contact info for those involved in psychosocial oncology in Canada
- ✓ maintaining professional credibility

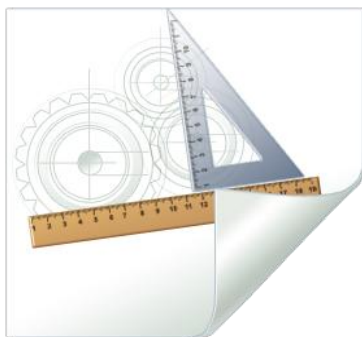
Some specific tools were suggested:

- ✓ a letter/email/bulletin to CAPO and CANO members (from key CAPO or CANO leaders);
  - The communication would have a PDF of important information, it would ask the recipient to crosslink their sites/communications with ours, materials would allow CO-Brand "organization logo" is a partner
- ✓ an announcement through CIHR targeting psychosocial cancer researchers
- ✓ word of mouth "member to member connections" (e.g. current CPOP members to colleagues or other researchers), taking responsibility for getting 1 other person aware of opportunities with CPOP
- ✓ funding appeals
- ✓ giving presentations, running workshops and or showing a presence at important relevant events such as multi-tiered conferences (e.g. CAPO, CANO)
- ✓ developing marketing materials such as postcards



## EVALUATION of the WORKSHOP

All participants were asked to complete a questionnaire evaluating their experience at the workshop. Possible responses could range from 1 (lowest) to 7 (highest). The most positive response was to the statement "I believe it is important to share information amongst CBOs, researchers, health professionals and others", where the average (mean) response was 6.9/7.



All other average ratings were above 5. Participants clearly left the workshop planning to contribute to the website (6.2) and use what they had learned in their own organizations (5.9). They were satisfied with the action plan developed (5.8) and had a better understanding of barriers to sustaining communities of practice (5.3), of current community of practice sustainability practices (5.0), and of how to promote the integration of cancer care and research (5.3). Most also felt they learned new ways to sustain

relationships that will help their organizations to exchange information in the future (5.1).

**General comments:**

*-Very stimulating and promising. Hope it will go on for a long time! Thank you, very well organized. Thank you all for respecting the schedule.*

*-Thank you Lynn, Rob & Kelly. SO much hard work and passion went into this! Thank you for your continued efforts. Venue, food, arrangements were excellent.*

*-Thank you!*

*-Excellent overall. Great job Lynne & Rob!*

**CONCLUSION**

As usual, the workshop really did require participants to work and, as usual, we did and very hard too. The enormous amount of thought and effort that went into planning for the sustainability of the CPOP community of practice and our online meeting space, CPOPonline, will pay off as the suggestions put forward during our 2009 meeting is gradually implemented over the coming years.

## LIST OF ACRONYMS

<b>CAPO</b>	Canadian Association of Psychosocial Oncology
<b>CBO</b>	community based organization (new term for NGO)
<b>CoP</b>	community of practice
<b>CPAC</b>	Canadian Partnership Against Cancer
<b>CPOP</b>	Canadian Psychosocial Oncology Partners
<b>KE</b>	knowledge exchange
<b>KT</b>	knowledge transfer

### **Note:**

*This report is a brief summary of the key workshop presentations and workshop feedback. More detailed information on knowledge exchange, communities of practice and capacity building and the event, including PowerPoint presentations, more comprehensive background information, and a copy of the report on the 2007 CBO survey can be found on CPOPonline, in the Document Repository section in 'CPOP reports and talks'. This report may be found there too.*

Dr. Lynne Robinson, Dalhousie University (School of Health and Human Performance)  
6230 South Street Halifax, NS B3H 3J5; Tel: 902.494.1154; Email: lynne.robinson@dal.ca

## REFERENCE

1. Supportive\_Care/\_Cancer\_Rehabilitation\_Workgroup. Canadian Strategy for Cancer Control: Supportive Care/Cancer Rehabilitation Workgroup Final Report. Available at: <http://209.217.127.72/csc/pdf/finalsupportiveJan2002.PDF>. Accessed June 1, 2006.