

Workshop:

**“Creating a Community for Knowledge
Exchange and Capacity Building in
Psychosocial Cancer Care”**

**Fort Garry Hotel, Winnipeg, MB
May 11 & 12, 2007**

REPORT

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**CAPO
ACOP**



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EXECUTIVE SUMMARY

This workshop was attended by 33 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 develop the vision of seamless integrated psychosocial cancer care, foster ongoing working relationships between attendees and develop sustainable action plans to create a community for knowledge exchange in psychosocial cancer care.

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.

BACKGROUND:

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. These founding organizations were: the Canadian Breast Cancer network, The Canadian Cancer Society, the Colorectal Cancer Association of Canada, Lung Cancer Canada, the Leukemia and Lymphoma Society of Canada, the National Ovarian Cancer Association, Ovarian Cancer Canada, Wellspring, RealTime Cancer, Willow Breast Cancer Support Canada, and Hope and Cope. The consensus from this first meeting was the need to develop:

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

The first step in developing these tools was to carry out a study of the KE practices and barriers to KE within Canadian psychosocial cancer CBOs. Thirteen CBOs were interviewed during the winter of 2007. The interviews were transcribed and the major themes regarding KE were extracted using qualitative research methodology. Findings from this survey were reported at the Winnipeg workshop and informed the discussions at the workshop.

CONTEXT:

Why This Initiative is Needed Now: The psychosocial context of individuals with cancer and their families

While each person's cancer journey is individual¹, 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 treatment¹. 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 fear¹ 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 potential¹. 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 convention 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.

We propose the creation of a knowledge exchange community to facilitate information sharing, knowledge translation, collaboration, and capacity building, transforming the “pillars” of psychosocial cancer care into partners.. Ultimately, patients and their families will benefit from a more integrated and collaborative system of psychosocial cancer care.

PURPOSE OF THE WORKSHOP:

The aims of the workshop were to:

- bring together key stakeholder groups in psychosocial cancer care to develop the vision of seamless integrated care and to foster ongoing working relationships
- share CBO survey results and generate an overview of current practices as well as barriers and enablers in knowledge exchange and research between CBOs, psychosocial and medical professionals, and psychosocial researchers
- develop a sustainable action plan for creating a community for knowledge exchange and capacity building in psychosocial cancer care
- generate a set of resources for participants, including funding, to support them in implementing the sustainable action plan
- share findings from this workshop and outcomes from the action plan at the next annual Canadian Association of Psychosocial Oncology (CAPO) conference and through publication

THE WORKSHOP

PARTICIPANTS:

The event was attended by 33 key participants with backgrounds in psychosocial cancer care including health care professionals, health researchers, and representatives from Canadian cancer CBOs. (A complete list of workshop participants is available on page 13 of this summary.)

ACTIVITIES:

The workshop began on Friday evening with an overview of the current state of affairs in psychosocial cancer knowledge exchange. Dr. Jerry Devins, a psychosocial researcher from Princess Margaret Hospital, Dr. Mary Jane Esplen, president of CAPO, and Dr. Marg Fitch, co-chair of the Rebalance Focus group of the CSCC each helped to “set the stage” for the work to be done. Jerry Devins reviewed the role of research, Mary Jane Esplen outlined CAPO’s possible role in the KE project and Marg Fitch offered an update on how “Implementing the Canadian Strategy on Cancer Control” might contribute . In addition, Drs. Lynne Robinson and Rob

Rutledge presented the findings from the CBO survey and outlined the workshop objectives and activities.

On Saturday morning, Lynne introduced the work with a brief overview of knowledge exchange and its relevance for the workshop participants. She presented a model of KE that emphasized a collaborative process, focusing on what information should be shared with which audience using which strategies. Kim Thiboldeaux, President and CEO of the Wellness Community, an international CBO headquartered in Washington DC, gave the keynote address “*Measuring outcomes and success in the non-profit world: a partnership approach*”. She described the Vision of the Wellness Community as being “the gold standard of psychosocial support for people affected by cancer”. She then focussed on how the Wellness Community uses community-initiated research collaborations to further science, and translate research into practical outcomes of use to researchers, survivors and their families, and the organization.

The rest of Saturday was taken up by a series of four group activities, These activities moved the group through considering current barriers to sharing information, what we want our information sharing system to accomplish and how that system would work (who would be in it, how and what would it communicate). Finally, we developed sustainable goals. Each participant developed a short term goal for his/her own organization. Then small groups came up with 3-4 short-term, national goals that could be accomplished and sustained over 1-2 years, followed by longer-term goals that we, as a group, could work towards.

Responses from the small group goal-setting exercise were sorted across the groups, summarizing common themes. Groups identified some clear barriers to sharing with each other. Grouping responses from the small group work revealed five essential tasks necessary to increase information sharing and an outline of what groups believed to be the best case scenarios as a consequence of that improved information sharing. For the most part, we have used the actual words of participants to give depth to each theme.

OUTCOMES:

The name change

Early in the 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).

Barriers

We began with the question “*What’s holding us back* from becoming better able to share with each other, across interdisciplinary boundaries?” Groups recognized two key barriers: a lack of linkages amongst researchers and the CBO community and a lack of knowledge about how to exchange information more effectively. In addition a number of other barriers were identified: *lack of time, lack of funding, lack of access to current information, lack of information on how to choose priorities, and potential competition:*

Lack of linkages between researchers and CBO community

- Researchers are not being rewarded/motivated to share information with NGOs

- Universities are not being motivated to stimulate capacity building/KE at the community level
- It is hard to make connections with (relevant) researchers

Lack of knowledge about how to exchange information between relevant stakeholders

Some of the key questions that participants wanted answers to were:

- How do we transfer knowledge from research to stakeholders?
- How do we engage the right people to help us in KE?
- What are the best mechanisms for dissemination?
- Dissemination does not equal information uptake – how do we maximize information uptake from our dissemination efforts?

Additional barriers

- It is hard to keep on top of current information
- There is a lot of information out there but who knows about the resources?
- It is difficult to find time to build capacities and expertise levels
- Choosing priorities is a difficult process
- There is a perceived threat by health care institutions (i.e.: job loss, competition for patients)
- Information dissemination is expensive!

Five essential tasks to facilitate information sharing

I: Develop some sort of central hub, clearinghouse or portal that will allow information sharing.

- Comprehensive membership in a community of practice
- Need a ‘clearinghouse’ or a portal that allows access to information re: chronic diseases/health promotion
- Develop a web-based resource for information sharing
- Develop a ‘clearinghouse’ for one-stop-shopping
- CPOP needs one-stop-shopping for resources/expertise/programming
- Develop a web-based portal
- Invent a portal that links patients/families, NGOs and Health care professionals
- Establish an evidence-based portal to share info
- An information service directed at health care professionals
- A central information hub
- Shared form of communicating

i) What our clearinghouse would do: specific tasks that participants identified:

Participants wanted the clearinghouse to link stakeholders, provide a means to share information about resources, and include an evaluation process.

- Links patients/families, NGOs and Health care professionals
- Want to increase communication:
 - With health care professionals
 - With other NGOs
- Need NGO-Service provider linkages at the programme level

- Expand referral services in both directions (NGO to hospitals and vice versa)
- Need effective ways to communicate ideas with multiple audiences (i.e.: community advisory board)
- Researchers can see NGOs and resources
- We would have easy access to information and researchers
- Inventory of resources such as people, expertise, volunteers, programs
- Identify valid programs and information about how to access them
- Everyone would know about our organization
- Have a built in evaluation mechanism

II: Develop relationship with CAPO

- Revisit links between CAPO and ‘us’ and build this relationship
 - Let CAPO become the navigator of information resources, best practice strategies
 - Have CAPO explore creating a “CBO arm” to be more effective at the community level
 - Develop a shared mission

III: Build capacity for multidisciplinary work

- Need a multidisciplinary team model that works
- Establish inclusion, equality, and communication between all groups
- Researchers, NGOs, health care professionals would benefit from having a member of the ‘other camp’ on their teams so to improve communication between groups
- Improve networking capacity for all groups
- Language/cross-cultural barriers (i.e.: jargon and meaning) need to be eliminated
- Different groups require different modes of communication (language, jargon)
- Reduce language/cultural barriers
- Need to develop respect for different areas of expertise

IV: Increase the research component to CBO work.

- Need to bridge the gap between ‘theoretical’ and ‘applied’ divisions of research culture
- Need a research/evaluation/ethics committee within NGO
- We (CBOs) would be consulted when new research is conducted
- Demystify psycho-social research
- Researchers need to work with knowledge ‘brokers’ to disseminate effectively

V: Acquire funding to facilitate sustainability

- FUNDING! Not just from government but from all sources
- Get funding for all issues at hand
 - Get money/foster sustainability
 - Get funding
- Need new strategy to get financial resources
- Dedicated government support would be helpful

Best case scenarios for our KE strategy

We asked the participants to brainstorm our vision of the KE strategy we would like to have when the process is completed. As one participant identified it, this is a “blue sky” or best case scenario. We asked participants to think of the ideal we want to aim for as a way of opening up our thinking to all possibilities. This kind of question also helps us to know what outcomes of the project we should be aiming for. Most groups identified the importance of creating a partnership and a number of broad principles for working together were identified. All groups emphasized the importance of working together to develop a KE strategy to exchange information with sectors that are pivotal to the work of CBOs. Finally there were a number of specific activities that groups felt the partnership could accomplish. Some of these can be accomplished short-term, others will require more long-term planning.

Need for partnerships

- Organizations need to be grounded by partnerships
- Everyone values and respects what we do/offer
- We want to expand our services
- Increased networking opportunities
- Need to include the patients’ voices

Broad principles:

- Define a clear vision/mandate for CPOP
 - Formalized questions/goals/priorities
 - Defined mutual objectives
- We need an ‘emerging model’ or a ‘living model’ that moves from a one-on-one focus to a broader, more effective communications model
- A goal to be COMPREHENSIVE
 - Develop seamless care through knowledge exchange
 - Recognize/fill gaps in communication strategies
 - Communicating needs to other partners
 - Develop an effective strategy to ensure awareness by consumers
- Recognize cultural diversity
- Use consultants
- Accessibility is key
- Cost-effectiveness

Need for a KE strategy:

- Establish best practice models for communication/marketing/language
- Understanding the process of engagement
- Develop a focus on sustainability of effective KE
- Establish community and organizational links
- Medical professionals would invite us to their conferences
- Need to learn to work with the media

Specific activities that we could accomplish:

- Develop an effective quality assurance process
- Screening of patient distress (develop a ‘triage’ system for clients)
- Avoid duplication of services
- Learn the language and the format that are best for the target audience
- Develop a roundtable for discussion and feedback to close the gaps
- Monthly ‘environmental scan’ of work and research
- Increase capacity for PAID help
- Multimedia Public Service Announcements
- Create a ‘psycho-social’ week
- Keeping in touch with each other through
 - Newsletter to partners
 - Conferences
 - Committee participation
- Conferences, forums, workshops
- Websites, listservs, podcasts, blogs
- Registry
- Printed materials, library
- Trade show (with ‘speed dating’)
 - Provide a mechanism to get to know organizations

WHO do we need in our community in order to help us develop the best possible KE process?

Most groups identified the three key players that had been invited to the workshop: CBOs, academics or researchers, and health professionals, but participants went well beyond this small group to “think outside the box”. Naturally, our participants identified users of health resources and their advocates and supporters, suggesting that we involve patients/survivors, their families, consultants who have had experience with illness, and committed advocates. Our groups also identified several sources of funding support, suggesting that we involve funders of research and philanthropists. We also recognized the value of developing industry partnerships with such potential resources as pharmaceutical companies and manufacturers, marketing executives, banks and insurance companies. In addition, groups identified additional stakeholders that could be involved in our work in some way, listing: knowledge brokers, policy makers and government as well as augmenting Canadian personnel with international linkages

Each person was asked to develop his or her own KE goal, one that the organization he or she represented could reasonably carry out in the next year. Development of this goal was intended to start organizations thinking about KE and to begin to build momentum towards change.

Goals:

As well as an organization level goal, each group was asked to come up with about three short-term, sustainable goals. Such a goal was described as a “National goal that workshop participants can achieve in 1-2 years”. The goals here are essentially the ones identified in the session. They have been re-ordered from the most straightforward and “do-able” to the more complex, as well as given a logical order (e.g. a leadership team must be established as a first step towards

reaching the other goals). It can easily be seen that the goals build on each other. Establishing a name, a vision and or mission for our group and for the products of our work together will help us to create action plans and can also help to “create a buzz about wellness” as the work of the group begins to draw attention.

Short-term goals:

- Establish a leadership team for shared goals
- Establish vision/mission
- Establish name of finished product (make it lay accessible)
 - Support attendance
- Establish a provincial network (i.e.: provincial CPOP)
- Environmental scan of what other related groups are doing to improve their KE practices (e.g. tobacco control efforts)
- Develop action plans
 - Create a ‘buzz’ about ‘wellness’
 - Make resources more accessible

Long-term goals:

- Develop a sustainable infrastructure
- CPAC – rebalance group and monitor activity
- Communicate that integrated, standardized, equal access psycho-social care is a core value for all groups (community, CBOs, health care professionals)
- Develop standards for CBO programs (CAPO can help by providing expertise)
- Stimulate a broader discussion around creating quality assurance methods for CBOs

CONCLUSION:

Overall, the participants in the CPOP workshop clearly identified a need for a partnership that would link 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 CAPO and would accomplish two broad goals:

- 1) it would support partners in developing the best possible KE strategies and
- 2) those KE strategies would open channels for **streamlining of services to survivors and their families**, 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 partners.

EVALUATION of the WORKSHOP:

All participants were asked to complete a questionnaire evaluating their experience at the workshop. The evaluation of the workshop was given ethical approval by the Dalhousie University Research Ethics Board. Participants were asked to respond to eight questions, ranking their responses on a 7 point scale with 1 being “Not at all” and 7 being “Very much”. As well as ranking responses, participants were given space to comment on every question. Because of time commitments, not every participant was able to attend the whole workshop. Of the participants, 22 returned evaluations. It can easily be seen that most participants agreed that information

sharing is important and that one of the strongest effects of the workshop was the new relationships that participants made. The lowest scores were for having a better understanding of current KE practices and belief that the action plan is sustainable. The responses to the question about KE practices probably reflects the relatively small amount of time devoted to informing participants about KE practices as well as the reality that some respondents, as they pointed out, “already had a solid understanding”. The lower response to the belief in the action plan probably reflects understandable scepticism about the commitment of the group. As one respondent stated: I’m not sure. I am hopeful but I do not have a sense of the commitment from the other participants.” This person went on to add “FYI – I am committed to this project!!!”. One of the biggest concerns expressed by our participants was whether or not funding for the project could be achieved. There was also a wide range of responses, ranging from 2 or 3 to 7 on many questions. Again this may reflect the wide range of knowledge and experience that participants brought to the workshop.

| # | Question | Average response (Mean, range) |
|---|---|--------------------------------|
| 1 | it is important to share information amongst NGOs, researchers, health professionals and others. | 6.91 (6-7) |
| 2 | made new relationships that will help my organization to exchange information in the future | 6.14 (2-7) |
| 3 | workshop has helped me understand how the integration of cancer care and research can be accomplished | 5.27 (2-7) |
| 4 | have a better understanding of current knowledge exchange practices | 4.82 (2-7) |
| 5 | have a better understanding of barriers to knowledge exchange. | 5.2 (2-7) |
| 6 | satisfied with the action plan developed | 5.23 (3-7) |
| 7 | believe the action plan is sustainable | 4.89 (4-7) |
| 8 | plan to use what I have learned in my own organization | 5.55 (5-7) |

Almost all of the overall comments were positive and participants appeared to feel that they had benefited from the opportunity to take part in the workshop. Some of the comments were:

“Thank you so much for including us/me. The benefits to us went beyond my expectations. I greatly respect the participants and the organizers. I am very thankful to Rob and Lynn for their inclusiveness, organizational skills, ability to stay with the mandate for the meeting and stay with the schedule.”

“I found this workshop to be invaluable in really forcing me to think concretely about how to make my research collaborative and community based from inception not just in terms of its results, this workshop felt like real knowledge exchange and I feel privileged to have been part of it.”

NEXT STEPS:

1. We are in discussions with CAPO about the best relationship between CPOP and CAPO so we can work together on common goals.
2. We have created a task group that will guide the development of a sustainable plan for knowledge exchange incorporating the key themes developed at the workshop session. The task group will include representatives from CAPO and CPOP.
3. As a start, the task group is working on a proposal to create an online clearinghouse that will offer “one-stop shopping” to cancer survivors and their families, health professionals, researchers, and others, providing information on cancer-relevant psychosocial services available Canada-wide as well as the evidence basis for psychosocial services. We will use this proposal to apply for funding.
4. The task group will pursue an ongoing working relationship with the Canadian Strategy for Cancer Control and specifically the ReBalance Focus Action Group on a KE strategy
5. All participants will be asked to respond to a follow-up questionnaire on their experiences at the workshop. The questionnaire will be sent out early in September. We encourage all participants to return that questionnaire, as it is an important part of our evaluation of this workshop and will guide us in future activities.
6. We are organizing a day-long seminar/conference intended specifically for Community-Based Organizations and our partners, to be held at the CAPO 2008 conference. The conference will be held in Halifax May 7-9 and our seminar will be held on the Friday. We hope to see you all there and encourage you to bring others who might strengthen our partnership.

LIST OF ACRONYMS:

| | |
|-------------|---|
| CAPO | Canadian Association of Psychosocial Oncology |
| CBO | community based organization (new term for NGO) |
| CPOP | Canadian Psychosocial Oncology Partners |
| KE | knowledge exchange |
| KT | knowledge transfer |
| NGO | non-government organization |

Note:

This report is a brief summary of the key workshop presentations and workshop feedback. More detailed information on knowledge exchange and capacity building and the event, including PowerPoint presentations, more comprehensive background information, and a copy of the report on the CBO survey can be requested through Lynne Robinson.

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