# Conference Summary

## New England Regional Comprehensive Cancer Control Survivorship Conference

October 18 -19, 2010: Best Western Executive Court Inn & Conference Center, Manchester, NH

**Conference Organized by:**
Massachusetts Comprehensive Cancer Control Coalition-
Regional Collaboration and Communication Subcommittee

**Sponsored by:**
American Cancer Society &
Massachusetts Survivorship Workgroup

# Overview & Summary

On October 18-19, 2010, the New England Regional Comprehensive Cancer Control Survivorship Conference was held in Manchester, New Hampshire, under funding from the American Cancer Society (ACS) New England Division and the Massachusetts Survivorship Workgroup. The overall goal of the conference was to foster a regional collaboration among the six New England states on issues related to cancer survivorship. Specifically, the conference objectives were:

1. Maximize networking opportunities to share information and resources related to cancer survivorship.
2. Create a viable regional network of New England States that focuses on emerging cancer survivorship issues.
3. Track outcomes of the conference to evaluate successes of future work together.

A total of 34 individuals attended the two-half day conference, which took place from 12:00P.M-5:00P.M. on day 1 and 8:00A.M.-1:00P.M. on day 2. While 31 participants attended in person, 3 individuals attended over the phone through a web conferencing system called GoToMeeting. Each New England state was invited to send 4 participants to the conference. Participants had to be affiliated with their state's comprehensive cancer control program and be interested in cancer survivorship. This resulted in a mix of participants including survivors, caregivers, comprehensive cancer control staff, and health care professionals from all six New England States. As indicated in Table 1, ACS, as a conference sponsor, had six attendees and the Massachusetts Survivorship Work had ninevolunteers. Two program officers from the Center for Disease Control and Prevention were also present.

**Table 1**: Conference Attendees per day

| Conference Attendees | Day 1 | Day 2 |
|---|---|---|
| State Representatives (Attended In-Person) | **MA**: 3 **ME**:1 **NH**: 4 **RI**: 3 **VT**: 3<br>*Total: 14* | **MA**:3 **ME**:2 **NH**: 4 **RI**: 3 **VT**: 2<br>*Total: 14* |
| State Representatives (Attended via Telephone) | **CT**: 2 **ME**: 1<br>*Total: 3* | **CT**: 3<br>*Total: 3* |
| American Cancer Society Representatives | 6 | 6 |
| Conference Volunteers/MA Survivorship Workgroup Committee | 9 | 9 |
| CDC Program Officers | 2 | 2 |
| **Total** | **34** | **34** |

On day one, Carol Curtiss, MSN, RN-BC led a keynote presentation on the current state of cancer survivorship in the U.S. This was followed by a presentation from each New England state highlighting their cancer survivorship initiatives and small roundtable discussions on gaps, overlaps in state efforts, and possible opportunities for collaborative work. On day two, participants attended one of four concurrent workgroup sessions, which were determined previously through a survey sent to conference participants. These sessions were:

- ❖ Treatment Summaries and Survivorship Care Plans
- ❖ How to Identify and Follow-Up Over Time on the Needs of Long Term Cancer Survivors
- ❖ Patient Navigation
- ❖ Development, Availability, and Dissemination of Survivorship Resources

Recommendations and action steps were developed in response to these emerging survivorship needs. At the culmination of the conference, CDC staff reflected on the events of the conference and representatives from each state made a commitment to work on one of the four listed survivorship workgroups.

A brief summary of the major points made during the state presentations and workgroup discussions are provided in the following sections.

## Day 1: State Presentations & Roundtable Discussions

During 20 minute presentations, each state reported on their program successes, challenges, and lessons learned using a standard template. A standard template was used to allow comparison of information among all states and to ensure that the goals of the conference were being met. It was evident that all states had a strong desire to meet the needs of cancer survivors and to work in collaboration with one another. As outlined in Table 2, all states reported working on a variety of survivorship initiatives ranging from a needs assessment to building new survivorship programs.

**Table 2**: Survivorship Initiatives by State

| State | Survivorship Initiatives |
|---|---|
| **Connecticut** | • Statewide needs assessment of cancer survivors and providers.<br>• Cancer survivorship education programs. |
| **Maine** | • Implementation of survivorship care pilot programs at 2 medical centers.<br>• Resource directory for patients and family by county/area. |
| **Massachusetts** | • Survivorship Summit in May, 2008.<br>• Physician Survey on Use of Cancer Treatment Summaries and Survivorship Care Plans.<br>• First New England Comprehensive Cancer Control Regional Conference on Survivorship. |
| **New Hampshire** | • Development and distribution of the brochure: “Cancer Survivorship, Your Plan of Care”.<br>• Cancer Survivor Needs Assessment. |
| **Rhode Island** | • Annual Cancer Summit for cancer survivors and health care providers.<br>• Implementation of the Survivorship and Treatment Surveys to determine the needs of cancer survivors. |
| **Vermont** | • Creation of the Vermont Cancer Network.<br>• Creation and implementation of the “Kindred Connections” peer-to-peer support program.<br>• Creation of the Cancer Survivor Community Study. |

*There were 3 areas of overlap in state efforts identified through roundtable discussions*:

- Implementation of survivorship care plans
- Needs assessment of cancer survivors
- Annual educational summits or conferences for survivors, health care professionals, and others.

*States also faced similar challenges and barriers to implementing these initiatives such as:*

- Funding
- Recruitment and retention of volunteers
- Lack of resource sharing among states
- Poor communication between health care organizations, hospitals, and other cancer groups
- Institutional barriers (e.g., time, staff support)
- Low survivor and provider participation rates in programs and surveys

*Opportunities for collaboration among all states were identified as:*

- Sharing findings on survivorship surveys and cancer trend data.
- Resource development and sharing tools (e.g., needs assessment surveys).
- Patient navigation: sharing best practices, cross state training of navigators, and exploring the potential role of patient navigation for cancer survivors in primary care settings.
- Developing cancer resources for newly diagnosed patients; tailored for special populations.
- Implementing survivorship care plans (e.g., sharing templates and implementation processes).

## Day 2: Challenges and Recommendations Outlined by Breakout Groups

### I. Treatment Summaries and Survivorship Care Plans

Based on recommendations from the Institute of Medicine, several New England states are implementing survivorship care plans to help meet the needs of cancer survivors. This workgroup discussed some of the challenges with implementing these plans and action steps that can be taken to increase usage at health care facilities. First, the workgroup discussed the challenges with the term cancer survivor. Specifically, whose definition are we using and who officially declares you a survivor?

*Other challenges discussed included*:

- ❖ Lack of reimbursement for survivorship care plans.
- ❖ No clear definition of the roles of patients, nurses, primary care providers, and oncologists.
- ❖ Hospitals' information systems are all so different making it difficult to access all of a patient's medical information.
- ❖ No standard survivorship care plan template available.
- ❖ Most survivorship care plans focus only on breast cancer patients.
- ❖ Templates are not available in multiple languages or geared towards populations with low levels of health literacy.

*Based on these challenges, the following recommendations were proposed by the group*:

- ❖ Review existing models/templates.
- ❖ Create a presentation on survivorship care plans/treatment summaries to obtain buy-in. Presentations should be tailored to different audiences (e.g., patients, providers, interpreters).
- ❖ Collaborate with the American College of Surgeons in shaping elements of the care plan.
- ❖ Work with the American Cancer Society on a legislative agenda focused on implementing standard use of survivorship care plans.

**Final Recommendation:** Engage in a New England workgroup to create a transitional plan for cancer survivors or recommend elements of a transitional care plan.

## II. Needs of Long Term Cancer Survivors

Cancer survivors face a number of long-term consequences as a result of a cancer diagnosis. However, there is still no consensus on the needs of cancer survivors and few studies have expanded our understanding of the physical and psychosocial issues related to survivorship. Therefore, this group discussed the challenges in identifying and obtaining long-term follow-up of cancer survivors.

*Specifically, the following areas were discussed*:

- No clear definition of what constitutes a "long-term" cancer survivor.
- Difficulties identifying long-term cancer survivors due to survivors lack of contact with cancer care providers after treatment.
- Primary Care Providers are not trained to deal with the long-term effects of cancer and its treatments in survivors.
- Survivor programs are vastly different in each facility and common standards/guidelines are needed.
- Few resources exist to meet the emotional and psychological needs of survivors.

*The following recommendations were proposed by the group:*

- Conduct a New England wide needs assessment and establish a survivor registry.
- Provide training for primary care physicians on how to identify and address the needs of long-term cancer survivors.
- Develop a one page document on the top needs of long-term cancer survivors.
- As part of the Electronic Medical Records, develop a reminder system for primary care physicians on what services cancer survivors need.

**Final Recommendation:** Develop a New England Survivorship Conference for Primary Care Physicians and others.

## III. Patient Navigation

Since the 1990s, patient navigation programs have been designed to address barriers to screening and cancer treatment among underserved populations. However, there is limited information on the efficacy of patient navigation programs and their impact on the health outcomes of survivors. As a result, this group explored the challenges of implementing and measuring the impact of patient navigation programs.

*Specifically, the following challenges were discussed:*

- Definition of patient navigation is too broad.
- Roles and responsibilities of patient navigators are not clearly defined.
- Many differences exist between rural and urban programs.
- Few resources available for cancer survivors.
- Need to increase the profile and importance of the patient navigator role.
- Need for quality metrics: measuring outcomes and worth of patient navigation programs

*The following recommendations were proposed by the group:*

- Work closely with the American College of Surgeon liaisons to make patient navigation and survivorship a priority.
- Engage in advocacy efforts that demonstrate the importance of patient navigator programs in health care facilities.
- Host a New England wide patient navigation and survivorship program with key presenters and opportunities for sharing best practices and challenges.

**Final Recommendation:** Establish a New England Patient Navigation Survivorship Program.

## IV. Development, Availability, and Dissemination of Survivorship Resources

Few resources, programs, and support services exist for cancer survivors who have completed treatment. This group discussed the needs and gaps in this area as well as possible strategies to help guide the development of more survivor programs.

*Specifically, the following areas were discussed:*

- Gaps in resources for pediatric cancer survivors and adult survivors who are at least 6 months out of treatment.
- Need for survivors’ resources is greater in rural areas.
- Long-term cancer survivors have difficulty finding resources when they have limited computer literacy or no access to the internet or computers.
- Few survivor programs and educational materials are tailored to undeserved communities (e.g., Blacks, Hispanics, and Tribal communities).
- No real sense of what the long-term needs of New England survivors are.
- Difficult to find out who survivors are and where they are located regionally.
- Evaluation of cancer resource centers in hospitals is needed to determine their impact and effectiveness.

*The following recommendations were proposed by the group:*

- Improve the American Cancer Society Resource database to include more survivor resources and increase access and awareness of these services.
- Conduct a regional needs assessment of survivor needs.
- Use the Northern New England cancer registry project and the CDC to obtain data on who and where survivors are located regionally.

**Final Recommendations:** 1. Create a regional survey to assess needs of cancer survivors. 2. Develop a process to improve the American Cancer Society Resource database.

## Day 2: Concluding Remarks and Next Steps

*New Regional Workgroups*

The New England Regional Comprehensive Cancer Control Survivorship Conference has set the foundation for the development of a New England wide action plan. This is the first time New England states will develop a viable network on issues of survivorship. To move forward with the recommendations set forth by the four workgroups sessions, conference attendees representing all six New England states have volunteered to take part in one of four corresponding regional workgroups. Each workgroup has an initial convener who will take the role of bringing the group members together after the culmination of the conference. Table 3 provides additional information on the workgroups' tasks and state representation.

**Table 3**: New England Ongoing Workgroup Committees

| Ongoing Committees | Role/Task | # of Representatives by State |
|---|---|---|
| Treatment Summaries and Survivorship Care Plans | Engage in a New England workgroup to create a transitional plan for cancer survivors or recommend elements of transitional care plan. | Total= 8<br>**CT**: 2 **ME**: 1 **MA**: 2 **NH**: 1 **RI**: 1 **VT**: 1 |
| Needs of Long-Term Cancer Survivors | Develop a New England Survivorship Conference for Primary Care Physicians and others. | Total= 11<br>**CT**: 1 **ME**: 0 **MA**: 7 **NH**: 0 **RI**: 2 **VT**: 1 |
| Patient Navigation* | Establish a New England Patient Navigation Survivorship Program | Total: 8<br>**CT**: 1 **ME**: 1 **MA**: 3 **NH**: 1 **RI**: 2 **VT**: 0 |
| Survivorship Resources | Create a regional survey to assess needs of cancer survivors & develop a process to improve the American Cancer Society Resource database | Total= 9<br>**CT**: 1 **ME**: 2 **MA**: 2 **NH**: 2 **RI**: 1 **VT**: 1 |

* Due to the lack of quality metrics for patient navigation programs in NE, the group will begin meeting in April of 2011.

*New England Regional Website: Establishing an Ongoing Communication Plan*

A fifth workgroup, called the interim Communication Group, has also been established to continue the work and momentum of the conference. This group will work towards developing a Regional Website consisting of resources, reading materials, and other tools, for use by all New England states. To help facilitate the process the group will use the Massachusetts Comprehensive Cancer Prevention and Control website for the first year to begin storing, documenting, and disseminating the conference findings and action plan (www.macompcancer.org). The Communication Group will then develop a plan for creating the Regional Website. This includes obtaining funding, establishing a domain name, developing website content, and developing a plan for updating and maintaining the website.

*Conference Follow-Up*

Kathryn Swaim, program manager at the University of Massachusetts Donahue Institute and coordinator of the Massachusetts Cancer Control Coalition, will be the initial convener for the Communications group. Additionally, she will manage the follow-up process for the conference and the other four regional workgroups.

Other next steps include:

- Creating a regional dissemination plan of conference findings*.
- Creating a document listing the resources needed to make this New England regional conference possible (e.g., planning process, lessons learned, budget, staff hours).
- Considering what the next regional gathering might look like.
- Developing a plan for generating scholarship monies for cancer survivors to attend the next regional conference.

Two CDC staff, who also attended the conference, have agreed to convey the findings of the conference to the CDC. This includes a request for a survivorship registry, conference call support, and funding for future conferences.

*Conference summary was written by Shioban Torres, a DrPH student at the Boston University School of Public Health who conducted her practicum with the MA Survivorship Workgroup.

## Evaluation and Participant Characteristics

At the end of the conference, twenty-one evaluation forms were completed, which represents 57% of total conference attendees. In general, the conference was very well received by participants with more than 80% stating they were “satisfied” or “very satisfied” with the overall quality of the sessions, speakers, and information presented. Participants viewed networking, learning of other state initiatives, and action planning as very important elements of the conference.

While most of the evaluations were positive, there were several areas where participants felt there was a need for improvement. This included:

- Allocating more time to developing an action plan
- Extending the conference to two full days
- Improving call-in technology for conference participants who are attending the conference via the telephone
- Building in some reflection time
- Healthier food options
- Better control of room temperature

As previously mentioned, there were 34 conference participants. Approximately, 13% of participants were male while 87% were females. The map below provides a geographic representation of conference participants and Table 4 provides additional information on the participants’ role.

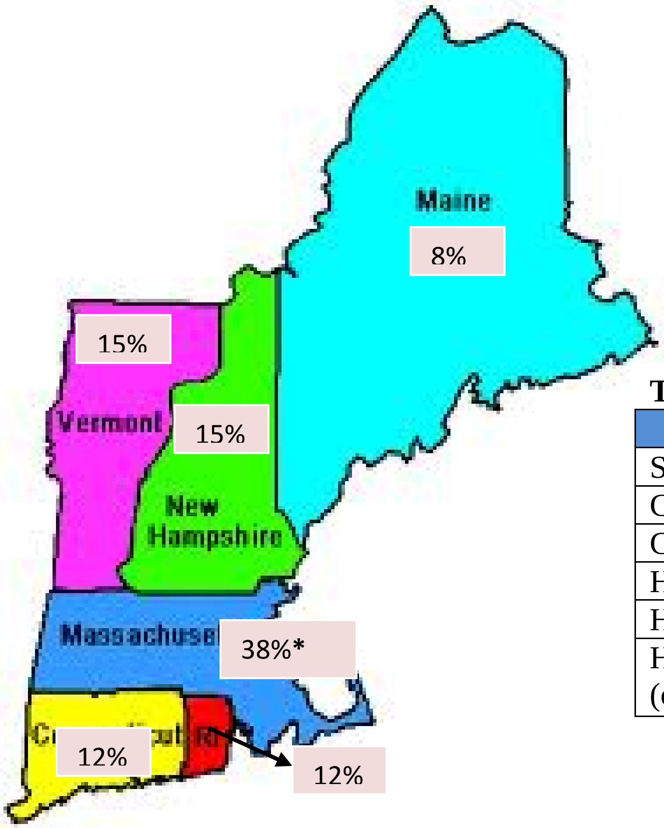

**Table 4:** Participant Role

| Role (Self-Description) | % |
|---|---|
| Survivor | 14% |
| Caregiver | 17% |
| Caregiver + Survivor | 8% |
| Health Care provider | 11% |
| Health Care Provider +/- Survivor/Caregiver | 14% |
| Health Care Professional (clinical/research/managerial) | 36% |

*Massachusetts has a higher percentage of conference participants because of a large number of conference volunteers.

*Overall, the New England Regional Comprehensive Cancer Control Survivorship Conference was a great success! Passion, excitement, and commitment are just a few words to describe how conference participants felt towards this new collaboration. Looking ahead, conference participants hope to make this an annual event as well as to develop an effective process for ongoing follow-up of the priorities established by the workgroups.*

*Again, thank you to all those who participated in the conference and made this event such a huge success!*