Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine
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Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine

George Shaler, MPH, Evaluation Coordinator

The author is on the staff of the
Edmund S. Muskie School of Public Service
Institute for Public Sector Innovation

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Edmund S. Muskie School of Public Service
Institute for Public Sector Innovation

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About the Muskie School of Public Service

The Edmund S. Muskie School of Public Service educates leaders, informs public policy, and strengthens civic life through its graduate degree programs, research institutes and public outreach activities. By making the essential connection between research, practice, and informed public policy, the School is dedicated to improving the lives of people of all ages, in every county in Maine and every state in the nation.

Acknowledgements

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- Barbara Poirier, University of Southern Maine, Edmund S. Muskie School of Public Service, Institute for Public Sector Innovation
Executive Summary

Currently, no published data exist regarding the type of rehabilitation and survivorship services that are being used or other services offered to cancer survivors in Maine. The findings of this assessment are the first statewide baseline data collected on cancer rehabilitation and survivorship services in Maine.

The assessment is designed to answer the following questions:

- What are the cancer treatment and follow-up needs of cancer patients seeking rehabilitation and survivorship services in Maine?
- What rehabilitation and survivorship services do cancer patients use in Maine?
- Are these services useful, affordable, and helpful?
- How did those living with cancer learn about these services?

All hospitals which provide cancer treatment in Maine were invited to participate in the assessment. Twenty hospitals/radiation oncology treatment centers took part in the survey. All but two of them returned completed surveys. Of the 18 facilities that returned surveys, six returned 50% or more of the surveys they received.

In order to get a representative sample, 2,160 assessments were disseminated during a two-month period (June and July 2004), with the goal of 1,200 completed surveys. Eight hundred and sixty one (n=861) or 40% of the 2,160 surveys were returned.

The assessment tool was developed by Ellen Sharp, M.Ed., a University of Maine graduate student intern with the Maine Comprehensive Cancer Control Program and CancerCare of Maine in consultation with the Maine Cancer Consortium’s Rehabilitation and Survivorship Work Group and staff from the Maine Center for Public Health. Each site was given a coded group number so their individual site data can be compared in aggregate and assessed individually during data analysis. Hospital staff submitted the completed assessments to the Edmund S. Muskie School of Public Service for data entry and analysis.

Key Findings

- The respondents’ mean age was 62.9.
- Fifty-two (52%) percent of the respondents were between the ages of 50-69.
- Females made up 64% of the respondents.
- The mean age at diagnosis was 59.5.
- The mean length of time with a cancer diagnosis was 3.1 years.
- Among 15 rehabilitation and survivorship services respondents were asked about, nutrition counseling (15.1%) services were used most. This means that at least 85% of respondents had either not used the service or left the question unanswered.
- Physicians were the most common referral source for all rehabilitation and survivorship services with the exception of alternative/complementary medicine.
- Among respondents who had used certain services, transportation services was the most helpful.
- The service most likely to be out of pocket expense was alternative/complementary medicine. The service least likely to be an out of pocket expense was speech therapy.
Project Overview
This assessment provides an opportunity to gain critical information about the needs of those who are receiving cancer treatment or follow-up rehabilitative care and survivorship services in Maine. This assessment provides information on the usefulness, affordability, and helpfulness of cancer rehabilitation and survivorship services, such as transportation, speech therapy, and counseling. One of the intended outcomes of this project is to begin collection of baseline data on cancer rehabilitation and survivorship services across the state. To date, there has been no collection of such data, which has made it challenging to make data-driven program decisions.

The data collection method consisted of surveying people who receive cancer treatment or follow-up at select Maine hospitals during June and July 2004. Patients received a copy of the survey while they were at a participating Maine hospital receiving oncology, radiation, chemotherapy or follow-up services. Returned surveys were entered into an Access Database developed by the Edmund S. Muskie School of Public Service for data entry and analysis purposes.

Introduction
With the change in age demography, the nature of Maine’s geographic terrain, and the patchwork nature of rural health service delivery, there is a great need for a statewide survey to assess the patient perspective on cancer survivorship. Currently, no published data exist regarding the type of rehabilitation and survivorship services that are being used or other services offered to cancer survivors in Maine. No data exist on the survivors’ perspective on the accessibility of the services, how they discovered the services and if their health insurance covers the costs or if transportation is a barrier. Furthermore, no data exist at a statewide level as to the referral pattern for survivor services from providers for support groups, homecare, hospice or alternative medicine adjunctive treatments or rehabilitation including occupational, physical and speech therapy. The assessment intends to identify the gaps in perceived patient access to services as related to distance, finances, advertising, and general rates of use of particular services.

Intended/Potential Use of Assessment Findings
The findings of this assessment are the first statewide baseline data collected on cancer rehabilitation and survivorship services in Maine. The accompanying results will inform Maine’s service providers and the Maine Cancer Consortium on the needs for and use of cancer rehabilitation and survivorship services. The findings will be used to make recommendations on how to enhance the system in order to reflect the reported needs of Maine residents living with cancer and seeking treatment or support services.

Assessment Design/ Location/ Timeframe
The study is a cross-sectional survey that utilized a convenience sample. The 90-item questionnaire was designed to be self administered to all participants who were receiving cancer treatment or follow-up services during June and July 2004. All hospitals which provide cancer treatment in Maine were invited to participate in the assessment, contingent upon approval of their internal IRB, if applicable. The questionnaire was piloted at two hospitals in the spring of 2004.

Assessment Questions
The assessment is designed to answer the following questions:

- What are the cancer treatment and follow-up needs of cancer patients seeking rehabilitation and survivorship services in Maine?
Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine

- What rehabilitation and survivorship services do cancer patients use in Maine?
- Are these services useful, affordable, and helpful?
- How did those living with cancer learn about these services?

**Inclusion/Exclusion Criteria**
The inclusion criteria for participation in the assessment are:
- An adult (18-89)
- Living in Maine
- Cancer diagnosis
- Receiving cancer treatment or follow-up services
- During June and July 2004

Hospital representatives were responsible for screening study participants to assure that all respondents met the inclusion criteria.

**Sampling**
On average, there are 608 Mainers diagnosed with cancer each month. A sampling plan for each participating hospital was developed based on the number of individuals seeking treatment at a particular hospital on a monthly basis. All adults at participating hospitals who are receiving cancer treatment or follow-up services were given the assessment to complete. Hospitals serving at least 100 patients a month were given two weeks to return their allotted number of surveys. Hospitals treating less than 50 patients a month were given a month. In order to get a representative sample, 2,160 assessments were disseminated during a two-month period (June and July 2004), with the goal of 1,200 completed surveys.

Twenty hospitals/radiation oncology treatment centers took part in the survey. All but two of them returned completed surveys. Of the 18 facilities that returned surveys, six returned 50% or more of the surveys they received. Only one returned all the surveys it received. Nine of the 11 American College of Surgeons (ACoS) Commission on Cancer approved hospitals in Maine participated in the survey and eight of these returned surveys. Ten non-ACoS Maine facilities participated as well. Please see Appendix A for more information on ACoS facilities.

**Consent Process**
Passive consent was used for this assessment. A cover letter was attached to the survey with the following language, “Your participation is voluntary. By completing the survey, you are giving your consent to participate.” Assessment forms did not contain any individual-identifying information.

**Study Instruments**
The assessment tool was developed by Ellen Sharp, M.Ed., a University of Maine graduate student intern with the Maine Comprehensive Cancer Control Program and CancerCare of Maine in consultation with the Maine Cancer Consortium’s Rehabilitation and Survivorship Work Group and staff from the Maine Center for Public Health. Please see Appendix B for a copy of the assessment tool and Appendix C for a list of Rehabilitation and Survivorship Work Group members.
The final survey protocols including the questionnaire and consent form were reviewed by representatives from the Maine Comprehensive Cancer Control Program, the Maine Center for Public Health, and Rehabilitation and Survivorship Work Group members. (Appendix C).

Data Collection and Analysis

Each site was given a coded group number so their individual site data can be compared in aggregate and assessed individually during data analysis. Hospital staff submitted the completed assessments to the Edmund S. Muskie School of Public Service for data entry and analysis. Data analysis was completed with SPSS software. Descriptive statistics were calculated to provide a general picture of the study sample with respect to demographics, including age, sex, date and type of cancer diagnosis, and name of hospital where treatment was received.
RESULTS

Section I. Demographics and Overall Responses

Eight Hundred And Sixty One (N=861) Or 40% Of The 2,160 Surveys Were Returned

Age and Gender of Respondents

Eight hundred and forty-three (n=843) or 98% of the survey respondents provided their age. The mean age for respondents was 62.9. Fifty-two (52%) percent of the respondents were between the ages of 50-69.

Table 1. Respondents by Age Cohorts & Mean Age

<table>
<thead>
<tr>
<th>Age Cohort</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-39*</td>
<td>29</td>
<td>3.4%</td>
</tr>
<tr>
<td>40-49</td>
<td>98</td>
<td>11.6%</td>
</tr>
<tr>
<td>50-59</td>
<td>207</td>
<td>24.6%</td>
</tr>
<tr>
<td>60-69</td>
<td>228</td>
<td>27.0%</td>
</tr>
<tr>
<td>70-79</td>
<td>190</td>
<td>22.5%</td>
</tr>
<tr>
<td>80-89</td>
<td>91</td>
<td>10.8%</td>
</tr>
<tr>
<td>Total</td>
<td>843</td>
<td>100.00%</td>
</tr>
</tbody>
</table>

* = No 18-19 year olds completed the survey.

Seven hundred and ninety-two (n=792) or 92% of the respondents indicated a gender. Of these, 64% were female and 36% were male (Table 2). Among American College of Surgeons (ACoS) Commission on Cancer approved hospitals in Maine, the breakdown was 61% female and 39% male, while 73% and 27% of non-ACoS respondents were female and male respectively. Please see the Appendix A for a listing of ACoS facilities in Maine.

Table 2. Respondents by Gender

<table>
<thead>
<tr>
<th></th>
<th>Overall (n=792)</th>
<th>ACoS (n=629)</th>
<th>Non-ACoS (n=163)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>63.6%</td>
<td>61.2%</td>
<td>73.0%</td>
</tr>
<tr>
<td>Male</td>
<td>36.4%</td>
<td>38.8%</td>
<td>27.0%</td>
</tr>
</tbody>
</table>

Primary Cancer Diagnoses Among Respondents

Seven hundred and sixty-three (n=763) or 89% of all respondents listed a cancer diagnosis or some type of diagnosis. A breast cancer diagnosis accounted for about a third (31.6%) of all primary diagnoses.

Females accounted for 65% of the 719 respondents who gave a diagnosis and selected a gender. A breast cancer diagnosis was the primary diagnosis for 49% of these women followed by gynecological (13%), leukemia/lymphoma/ myeloma (12%), lung (9%), and colorectal (8%).
Prostate/testicular cancer (30%) was the leading primary cancer diagnosis for male respondents followed by leukemia/lymphoma/myeloma (22%), lung (15%), colorectal (10%), and head and neck/thyroid, and esophagus (5%).

**Graph 1. Primary Cancer Diagnoses among Respondents**

Prostate/testicular cancer (30%) was the leading primary cancer diagnosis for male respondents followed by leukemia/lymphoma/myeloma (22%), lung (15%), colorectal (10%), and head and neck/thyroid, and esophagus (5%).

**Age at Diagnosis**

Eight hundred and two (n=802) or 93% of the respondents indicated their current age and year of diagnosis. This enabled the Muskie School to calculate a crude age at diagnosis. Since the month and date were not specified, the Muskie School determined the age at diagnosis by taking the current year and subtracting the diagnosis year. Then taking this difference and subtracting it from their current age.

For example, respondent X gives their current age as 41 (in 2004) and the year of their cancer diagnosis as 1993. The age at diagnosis is calculated as follows: current year (2004) - diagnosis year (1993) = 11. Current age (41) - year difference (11) = age at diagnosis (30).

The mean age when cancer was first diagnosed for the 802 respondents mentioned above was 59.5 years. Among these respondents the average length of time with a cancer diagnosis was 3.1 years. Length of time ranged from 0 (diagnosed this year) to 51 years. Please note that some people may have had a subsequent diagnosis.

<table>
<thead>
<tr>
<th>Table 3. Age at Diagnosis and Length of Time (in years) with Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age at Diagnosis (n=802)</td>
</tr>
<tr>
<td>Mean Length of Time with Cancer Diagnosis</td>
</tr>
<tr>
<td>Length of Time with Cancer Diagnosis (range)</td>
</tr>
<tr>
<td>Year of Diagnosis</td>
</tr>
</tbody>
</table>

**Cancer Treatment**

Eight hundred and twenty-two (n=822) or 95% of the survey respondents answered the question whether they were currently receiving treatment for a cancer diagnosis. Of the 822, 66% and 34% answered “Yes”
and “No” respectively. Women (69%) tended to be currently receiving treatment more than men (62%). Among age cohorts (20-39, 40-49, 50-59, 60-69, 70-79, and 80-89), no age group reported large difference when it came to this question.

**Returned Surveys by Facility Type**

Among ACoS approved hospitals in Maine, the response rate was 45% compared to 28% for non-ACoS facilities. ACoS facilities returned 79% of all the surveys entered by the Muskie School. For more information on responses, please see Appendix D.

**Service Use Domains**

Respondents were asked to respond to the following question, “Have you used this service,” to 15 different services (Table 4). The service used most often was nutrition counseling (15.1%) followed by education and support groups (14.4%). The services used least often were hospice (2.8%) and speech therapy (2.2%).

**Table 4. Have you used this service? Type of Responses (in the order the question was asked) (n=861)**

<table>
<thead>
<tr>
<th>Service</th>
<th>% Yes</th>
<th>% No</th>
<th>% NR*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>9.5%</td>
<td>85.1%</td>
<td>5.3%</td>
</tr>
<tr>
<td>Lodging</td>
<td>6.4%</td>
<td>85.9%</td>
<td>7.7%</td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>10.5%</td>
<td>80.0%</td>
<td>9.5%</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>10.5%</td>
<td>80.6%</td>
<td>9.9%</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>5.0%</td>
<td>81.8%</td>
<td>13.2%</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>5.7%</td>
<td>82.8%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>2.2%</td>
<td>85.5%</td>
<td>12.3%</td>
</tr>
<tr>
<td>Education &amp; Support Groups</td>
<td>14.4%</td>
<td>74.7%</td>
<td>10.9%</td>
</tr>
<tr>
<td>Counseling</td>
<td>9.4%</td>
<td>78.7%</td>
<td>11.8%</td>
</tr>
<tr>
<td>Nutrition Counseling</td>
<td>15.1%</td>
<td>73.2%</td>
<td>11.7%</td>
</tr>
<tr>
<td>Pain Management</td>
<td>12.9%</td>
<td>74.4%</td>
<td>12.7%</td>
</tr>
<tr>
<td>Alt./Complementary Medicine</td>
<td>7.7%</td>
<td>79.7%</td>
<td>12.7%</td>
</tr>
<tr>
<td>Home Care</td>
<td>13.8%</td>
<td>74.9%</td>
<td>11.3%</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>7.1%</td>
<td>78.2%</td>
<td>14.8%</td>
</tr>
<tr>
<td>Hospice</td>
<td>2.8%</td>
<td>84.1%</td>
<td>13.1%</td>
</tr>
</tbody>
</table>

* NR = No Response

On average, each respondent used 1.3 of the 15 services. Among respondents who used at least one service, the average was 2.6 services. Almost half (49%) of the 861 respondents did not use any of the 15 services and only four respondents used all of them.

The non-responses to these questions are noteworthy. For the first four services (transportation, lodging, financial assistance, and physical therapy) on the survey, the no responses were less than 10%, even though they were not the most used services. With all subsequent services, the non-response rate was over 10%. Graph 2 on the next page charts the non-response rate in the order in which the service question was asked.

Non-ACoS respondents were more apt to have used rehabilitation and survivorship services than ACoS respondents. As table 5 on page nine indicates, non-ACoS respondents used the first nine services more than their ACoS counterparts. It should also be noted that non-ACoS respondents only make up 21% of all respondents. When the results are weighted to give ACoS and non-ACoS equal representation in the sample, education and support group services would be the most used service.
Graph 2. Percentage of No Responses by Service Domain
Section II. Respondents Who Have Used the Services

Referral Sources
If respondents used a service they were then asked, “How did you hear about this service?” The respondents were given eleven choices including “other.” They could check all that apply. Table 6 shows the referral sources for the various services.

Physicians were the most common referral source for all rehabilitation and survivorship services with the exception of alternative/complementary medicine. In this case they were second to family/friend. With all but three services - lodging, financial assistance, and alternative/complementary medicine - more than half of the respondents indicated that a doctor/physician was one of or the only referral source. Nurses were the next most common source of referral information followed by social worker and then family/friend.

Table 5. Have you used this service? Responses by Facility Type (in rank order) (n=861)

<table>
<thead>
<tr>
<th>Service</th>
<th>% Yes (Overall)</th>
<th>% Yes - Weighted* (Overall)</th>
<th>% Yes (ACoS) – (n=676)</th>
<th>% Yes – (Non-ACoS) (n=185)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition Counseling</td>
<td>15.1%</td>
<td>15.5%</td>
<td>14.8%</td>
<td>16.2%</td>
</tr>
<tr>
<td>Educ. &amp; Support Groups</td>
<td>14.4%</td>
<td>16.0%</td>
<td>13.2%</td>
<td>18.9%</td>
</tr>
<tr>
<td>Home Care</td>
<td>13.8%</td>
<td>15.3%</td>
<td>12.7%</td>
<td>17.8%</td>
</tr>
<tr>
<td>Pain Management</td>
<td>12.9%</td>
<td>13.3%</td>
<td>12.6%</td>
<td>14.1%</td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>10.5%</td>
<td>11.6%</td>
<td>9.6%</td>
<td>13.5%</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>10.5%</td>
<td>12.3%</td>
<td>9.0%</td>
<td>15.7%</td>
</tr>
<tr>
<td>Transportation</td>
<td>9.5%</td>
<td>11.0%</td>
<td>8.4%</td>
<td>13.6%</td>
</tr>
<tr>
<td>Counseling</td>
<td>9.4%</td>
<td>10.5%</td>
<td>8.6%</td>
<td>12.4%</td>
</tr>
<tr>
<td>Alt./Complement. Medicine</td>
<td>7.7%</td>
<td>8.4%</td>
<td>7.1%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>7.1%</td>
<td>6.5%</td>
<td>7.5%</td>
<td>5.4%</td>
</tr>
<tr>
<td>Lodging</td>
<td>6.4%</td>
<td>5.2%</td>
<td>7.2%</td>
<td>3.2%</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>5.7%</td>
<td>5.6%</td>
<td>5.8%</td>
<td>5.4%</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>5.0%</td>
<td>4.8%</td>
<td>5.2%</td>
<td>4.3%</td>
</tr>
<tr>
<td>Hospice</td>
<td>2.8%</td>
<td>2.8%</td>
<td>2.8%</td>
<td>2.7%</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>2.2%</td>
<td>2.0%</td>
<td>2.4%</td>
<td>1.6%</td>
</tr>
</tbody>
</table>
* = Sample weighted to give ACoS and non-ACoS facilities equal representation

Table 6. Referral Sources

<table>
<thead>
<tr>
<th>Service</th>
<th>Doctor</th>
<th>Family</th>
<th>Friend</th>
<th>Nurse</th>
<th>Social</th>
<th>Worker</th>
<th>Clergy</th>
<th>Brochure</th>
<th>Newspaper</th>
<th>TV</th>
<th>Phone</th>
<th>Help</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation (n=82)</td>
<td>54%</td>
<td>27%</td>
<td>16%</td>
<td>18%</td>
<td>0%</td>
<td>5%</td>
<td>1%</td>
<td>1%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>9%</td>
</tr>
<tr>
<td>Lodging (n=55)</td>
<td>46%</td>
<td>26%</td>
<td>16%</td>
<td>18%</td>
<td>0%</td>
<td>4%</td>
<td>0%</td>
<td>2%</td>
<td>2%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>Financial Assistance (n=84)</td>
<td>41%</td>
<td>23%</td>
<td>24%</td>
<td>37%</td>
<td>1%</td>
<td>5%</td>
<td>0%</td>
<td>1%</td>
<td>0%</td>
<td>1%</td>
<td>0%</td>
<td>1%</td>
<td>12%</td>
</tr>
<tr>
<td>Physical Therapy (n=88)</td>
<td>82%</td>
<td>10%</td>
<td>34%</td>
<td>23%</td>
<td>1%</td>
<td>5%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>1%</td>
<td>0%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Lymphedema (n=41)</td>
<td>90%</td>
<td>7%</td>
<td>24%</td>
<td>5%</td>
<td>0%</td>
<td>2%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Occupational Therapy (n=48)</td>
<td>71%</td>
<td>15%</td>
<td>35%</td>
<td>38%</td>
<td>2%</td>
<td>4%</td>
<td>2%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>Speech Therapy (n=19)</td>
<td>84%</td>
<td>26%</td>
<td>21%</td>
<td>26%</td>
<td>5%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Ed. &amp; Support Groups (n=122)</td>
<td>57%</td>
<td>25%</td>
<td>50%</td>
<td>30%</td>
<td>2%</td>
<td>18%</td>
<td>4%</td>
<td>1%</td>
<td>2%</td>
<td>6%</td>
<td>7%</td>
<td>6%</td>
<td>8%</td>
</tr>
<tr>
<td>Counseling (n=77)</td>
<td>68%</td>
<td>20%</td>
<td>35%</td>
<td>42%</td>
<td>8%</td>
<td>7%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
<td>4%</td>
<td>4%</td>
</tr>
</tbody>
</table>
Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine

October 15, 2004
Edmund S. Muskie School of Public Service, Institute for Public Sector Innovation

Service Characteristics

If respondents used a service they were then asked a series of follow-up questions regarding their satisfaction with the services. The answers to these questions are in Table 7.

Among respondents answering “Yes” to the question “Have you used this service,” transportation was the most helpful service (95%) followed by home care (93%). With the exception of hospice and speech therapy services, at least 75% of respondents found each of the services helpful.

With the exception of lymphedema services, a majority of respondents indicated that services were helpful to family members. Lodging services were the most helpful service for families.

A majority of respondents indicated that they were able to use most of services within 30 miles of their home, the exception being lodging services. This is not surprising since most people who reside less than 30 miles from a treatment facility probably commute and would not have a need for lodging services.

Table 7. Service Quality and Availability

<table>
<thead>
<tr>
<th>Service</th>
<th>Did this service help you? (% Yes)</th>
<th>Did this service help your family? (% Yes)</th>
<th>Did you use this service within 30 miles of your home? (% Yes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation (n=82)</td>
<td>95%</td>
<td>74%</td>
<td>63%</td>
</tr>
<tr>
<td>Lodging (n=55)</td>
<td>87%</td>
<td>82%</td>
<td>34%</td>
</tr>
<tr>
<td>Financial Assistance (n=90)</td>
<td>83%</td>
<td>59%</td>
<td>60%</td>
</tr>
<tr>
<td>Physical Therapy (n=90)</td>
<td>83%</td>
<td>49%</td>
<td>72%</td>
</tr>
<tr>
<td>Lymphedema (n=43)</td>
<td>77%</td>
<td>19%</td>
<td>56%</td>
</tr>
<tr>
<td>Occupational Therapy (n=49)</td>
<td>82%</td>
<td>63%</td>
<td>55%</td>
</tr>
<tr>
<td>Speech Therapy (n=19)</td>
<td>68%</td>
<td>53%</td>
<td>53%</td>
</tr>
<tr>
<td>Ed. &amp; Support Groups (n=124)</td>
<td>82%</td>
<td>52%</td>
<td>71%</td>
</tr>
<tr>
<td>Counseling (n=81)</td>
<td>82%</td>
<td>68%</td>
<td>68%</td>
</tr>
<tr>
<td>Nutritional Counseling (n=130)</td>
<td>84%</td>
<td>55%</td>
<td>63%</td>
</tr>
<tr>
<td>Pain Management (n=111)</td>
<td>84%</td>
<td>52%</td>
<td>64%</td>
</tr>
<tr>
<td>Alt./ Complement. Medicine (n=66)</td>
<td>83%</td>
<td>53%</td>
<td>73%</td>
</tr>
<tr>
<td>Home Care (n=119)</td>
<td>93%</td>
<td>74%</td>
<td>85%</td>
</tr>
<tr>
<td>Palliative Care (n=61)</td>
<td>89%</td>
<td>67%</td>
<td>66%</td>
</tr>
<tr>
<td>Hospice (n=24)</td>
<td>63%</td>
<td>58%</td>
<td>54%</td>
</tr>
</tbody>
</table>

(n is the number of people who answered yes to the previous question, “Have you used this service” and answered this question.)
Payment for Services
For those who answered yes to the original question, “Have you used this service,” respondents were asked to respond to the following question, “How did you pay for this service?” Respondents indicated that most clinical and rehabilitative services were covered by their health insurance coverage. For example, 91% of respondents who used home care services had this service covered by health insurance. The service least likely to be covered by health insurance was education and support groups. Nearly three-quarters of respondents stated that this service was free to them.

The services most likely to be out of pocket expenses were alternative/complementary medicine (55%) and lodging (48%). The services least likely to be an out of pocket expense were speech therapy and hospice.

Some service domains generated several additional “other” responses. With financial assistance, one in three people providing an “other” response said MaineCare or Medicare. Likewise, nearly half of the people who provided an “other” option with transportation services mentioned MaineCare or Medicare.

Table 8. Payment of Services (How did you pay for this service - check all that apply).

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Health Insurance (% Yes)</th>
<th>On my own (% Yes)</th>
<th>Service was Free (% Yes)</th>
<th>Other (% Yes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation (n=78)</td>
<td>41%</td>
<td>13%</td>
<td>44%</td>
<td>19%</td>
</tr>
<tr>
<td>Lodging (n=50)</td>
<td>32%</td>
<td>48%</td>
<td>22%</td>
<td>16%</td>
</tr>
<tr>
<td>Financial Assistance (n=80)</td>
<td>34%</td>
<td>14%</td>
<td>50%</td>
<td>39%</td>
</tr>
<tr>
<td>Physical Therapy (n=79)</td>
<td>85%</td>
<td>11%</td>
<td>8%</td>
<td>13%</td>
</tr>
<tr>
<td>Lymphedema (n=35)</td>
<td>83%</td>
<td>23%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Occupational Therapy (n=45)</td>
<td>87%</td>
<td>9%</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Speech Therapy (n=15)</td>
<td>87%</td>
<td>0%</td>
<td>13%</td>
<td>0%</td>
</tr>
<tr>
<td>Ed. &amp; Support Groups (n=104)</td>
<td>22%</td>
<td>5%</td>
<td>74%</td>
<td>3%</td>
</tr>
<tr>
<td>Counseling (n=70)</td>
<td>59%</td>
<td>17%</td>
<td>36%</td>
<td>6%</td>
</tr>
<tr>
<td>Nutritional Counseling (n=112)</td>
<td>52%</td>
<td>11%</td>
<td>36%</td>
<td>9%</td>
</tr>
<tr>
<td>Pain Management (n=93)</td>
<td>75%</td>
<td>14%</td>
<td>15%</td>
<td>9%</td>
</tr>
<tr>
<td>Alt./Complement. Medicine (n=60)</td>
<td>28%</td>
<td>55%</td>
<td>25%</td>
<td>7%</td>
</tr>
<tr>
<td>Home Care (n=111)</td>
<td>91%</td>
<td>3%</td>
<td>4%</td>
<td>12%</td>
</tr>
<tr>
<td>Palliative Care (n=52)</td>
<td>65%</td>
<td>8%</td>
<td>29%</td>
<td>6%</td>
</tr>
<tr>
<td>Hospice (n=16)</td>
<td>63%</td>
<td>0%</td>
<td>31%</td>
<td>6%</td>
</tr>
</tbody>
</table>
Section III. Respondents Who Did Not Use the Services

No Responses
Most people completing the surveys answered “No” to the question, “Have you used this service?” People responding no were given five choices to choose from to explain their answer. In many cases, the person responding no did not provide a reason.

Of those that did check a reason(s), most chose “I do not have a need for the service.” Among those responding to this question, speech therapy (94%), lodging (93%), hospice (92%), and occupational therapy (90%) were checked the most often. Most people were aware of the various services, though 30% of responders answering no were not aware of alternative/complementary medicine services.

Most people did not provide an “other” response; however, the education and support group service domain was the exception. With this service, many people said it was inconvenient in their situation, too far, and/or not at the right time.

Table 9. Respondents answering no to the question, “Have you used this service?” Reasons - (check all that apply).

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of Respondents answering “No”</th>
<th>Number of Respondents answering “No” who provided a reason*</th>
<th>I do not have a need for the service (% Yes)</th>
<th>The service was not available (% Yes)</th>
<th>I could not afford the service (% Yes)</th>
<th>I was not aware of the service (% Yes)</th>
<th>Other (% Yes)</th>
<th>Number of respondents not answering the question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>733</td>
<td>565</td>
<td>86%</td>
<td>1%</td>
<td>&lt;1%</td>
<td>20%</td>
<td>3%</td>
<td>46</td>
</tr>
<tr>
<td>Lodging</td>
<td>740</td>
<td>532</td>
<td>93%</td>
<td>1%</td>
<td>1%</td>
<td>13%</td>
<td>1%</td>
<td>66</td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>689</td>
<td>461</td>
<td>76%</td>
<td>1%</td>
<td>&lt;1%</td>
<td>25%</td>
<td>6%</td>
<td>82</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>694</td>
<td>458</td>
<td>85%</td>
<td>1%</td>
<td>&lt;1%</td>
<td>15%</td>
<td>3%</td>
<td>77</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>704</td>
<td>426</td>
<td>88%</td>
<td>&lt;1%</td>
<td>1%</td>
<td>12%</td>
<td>5%</td>
<td>114</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>713</td>
<td>407</td>
<td>90%</td>
<td>&lt;1%</td>
<td>&lt;1%</td>
<td>13%</td>
<td>1%</td>
<td>99</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>736</td>
<td>460</td>
<td>94%</td>
<td>0%</td>
<td>&lt;1%</td>
<td>9%</td>
<td>1%</td>
<td>106</td>
</tr>
<tr>
<td>Ed. &amp; Support Groups</td>
<td>643</td>
<td>374</td>
<td>77%</td>
<td>1%</td>
<td>&lt;1%</td>
<td>13%</td>
<td>11%</td>
<td>94</td>
</tr>
<tr>
<td>Counseling</td>
<td>678</td>
<td>404</td>
<td>81%</td>
<td>1%</td>
<td>1%</td>
<td>17%</td>
<td>6%</td>
<td>102</td>
</tr>
<tr>
<td>Nutritional Counseling</td>
<td>630</td>
<td>370</td>
<td>80%</td>
<td>1%</td>
<td>1%</td>
<td>18%</td>
<td>4%</td>
<td>101</td>
</tr>
<tr>
<td>Pain Management</td>
<td>641</td>
<td>400</td>
<td>86%</td>
<td>1%</td>
<td>&lt;1%</td>
<td>15%</td>
<td>3%</td>
<td>109</td>
</tr>
<tr>
<td>Alt./Complement. Medicine</td>
<td>686</td>
<td>405</td>
<td>70%</td>
<td>1%</td>
<td>2%</td>
<td>30%</td>
<td>2%</td>
<td>109</td>
</tr>
<tr>
<td>Home Care</td>
<td>645</td>
<td>399</td>
<td>87%</td>
<td>1%</td>
<td>1%</td>
<td>13%</td>
<td>3%</td>
<td>97</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>673</td>
<td>397</td>
<td>79%</td>
<td>1%</td>
<td>1%</td>
<td>21%</td>
<td>2%</td>
<td>127</td>
</tr>
<tr>
<td>Hospice</td>
<td>724</td>
<td>443</td>
<td>92%</td>
<td>&lt;1%</td>
<td>1%</td>
<td>8%</td>
<td>2%</td>
<td>113</td>
</tr>
</tbody>
</table>

* = Percentages are based on the number in this column.
Awareness of Services - Respondents Answering “No”

Respondents who answered no to the question, “Have you used this service,” were subsequently asked if they heard about the service. The percentage figures below are based on those answering yes, no, or left in unanswered.

The services respondents answering no had heard the most about were education and support groups (33%), transportation (31%), and hospice (30%). The services these responders had heard the least about were lymphedema (10%), alternative/ complementary medicine (11%), and palliative care (11%).

With the exception of education and support groups, more people had not heard of the particular service than those that did.

Table 10. Awareness of Service - Have you heard about this service? (Respondents previously answering no to the question, “Have you used this service?”)

<table>
<thead>
<tr>
<th>Service</th>
<th>Number of Respondents who did not use service</th>
<th>Have you heard about this service? (% Yes)</th>
<th>Have you heard about this service? (% No)</th>
<th>Have you heard about this service? (% NR*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>733</td>
<td>31%</td>
<td>50%</td>
<td>19%</td>
</tr>
<tr>
<td>Lodging</td>
<td>740</td>
<td>22%</td>
<td>47%</td>
<td>31%</td>
</tr>
<tr>
<td>Financial Assistance</td>
<td>689</td>
<td>19%</td>
<td>50%</td>
<td>31%</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>694</td>
<td>19%</td>
<td>43%</td>
<td>38%</td>
</tr>
<tr>
<td>Lymphedema</td>
<td>704</td>
<td>10%</td>
<td>49%</td>
<td>41%</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>713</td>
<td>14%</td>
<td>45%</td>
<td>41%</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>736</td>
<td>12%</td>
<td>44%</td>
<td>43%</td>
</tr>
<tr>
<td>Ed. &amp; Support Groups</td>
<td>643</td>
<td>33%</td>
<td>29%</td>
<td>39%</td>
</tr>
<tr>
<td>Counseling</td>
<td>678</td>
<td>26%</td>
<td>35%</td>
<td>39%</td>
</tr>
<tr>
<td>Nutritional Counseling</td>
<td>630</td>
<td>24%</td>
<td>37%</td>
<td>39%</td>
</tr>
<tr>
<td>Pain Management</td>
<td>641</td>
<td>24%</td>
<td>37%</td>
<td>39%</td>
</tr>
<tr>
<td>Alt./Complement. Medicine</td>
<td>686</td>
<td>11%</td>
<td>48%</td>
<td>41%</td>
</tr>
<tr>
<td>Home Care</td>
<td>645</td>
<td>19%</td>
<td>39%</td>
<td>42%</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>673</td>
<td>11%</td>
<td>48%</td>
<td>41%</td>
</tr>
<tr>
<td>Hospice</td>
<td>724</td>
<td>30%</td>
<td>31%</td>
<td>40%</td>
</tr>
</tbody>
</table>

*NR = No response

If a responder answering no had heard about the service they were asked, “How did you hear about this service?” They could check all that apply.

The answers below differ with those in Table 6. The responses in Table 6 are based on people who have used the 15 services. The answers below reflect respondents who did not use the service(s) and their awareness, or lack thereof, of the rehabilitative and survivorship services and how they obtained that information. The sources of information for the 15 services are fairly evenly spread among doctors, family/ friends, nurses, social workers, and brochures with doctors and nurses leading the way.
### Table 11. How did you hear about this service? (Check all that apply) - People who did not use services

<table>
<thead>
<tr>
<th>Service</th>
<th>Doctor</th>
<th>Family</th>
<th>Friend</th>
<th>Nurse</th>
<th>Social Worker</th>
<th>Clergy</th>
<th>Brochure</th>
<th>Newspaper</th>
<th>TV</th>
<th>Phone help line</th>
<th>Web/Internet</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation (n=204)</td>
<td>25%</td>
<td>26%</td>
<td>28%</td>
<td>14%</td>
<td>0%</td>
<td>17%</td>
<td>6%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>1%</td>
<td>12%</td>
</tr>
<tr>
<td>Lodging (n=147)</td>
<td>20%</td>
<td>29%</td>
<td>27%</td>
<td>18%</td>
<td>0%</td>
<td>19%</td>
<td>6%</td>
<td>13%</td>
<td>0%</td>
<td>1%</td>
<td>1%</td>
<td>13%</td>
</tr>
<tr>
<td>Financial Assistance (n=108)</td>
<td>18%</td>
<td>15%</td>
<td>35%</td>
<td>22%</td>
<td>0%</td>
<td>19%</td>
<td>3%</td>
<td>4%</td>
<td>0%</td>
<td>2%</td>
<td>1%</td>
<td>13%</td>
</tr>
<tr>
<td>Physical Therapy (n=110)</td>
<td>38%</td>
<td>25%</td>
<td>33%</td>
<td>10%</td>
<td>0%</td>
<td>23%</td>
<td>4%</td>
<td>3%</td>
<td>0%</td>
<td>1%</td>
<td>1%</td>
<td>13%</td>
</tr>
<tr>
<td>Lymphedema (n=63)</td>
<td>56%</td>
<td>19%</td>
<td>29%</td>
<td>3%</td>
<td>0%</td>
<td>19%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>13%</td>
</tr>
<tr>
<td>Occupational Therapy (n=81)</td>
<td>32%</td>
<td>22%</td>
<td>40%</td>
<td>10%</td>
<td>0%</td>
<td>28%</td>
<td>7%</td>
<td>9%</td>
<td>0%</td>
<td>1%</td>
<td>1%</td>
<td>11%</td>
</tr>
<tr>
<td>Speech Therapy (n=72)</td>
<td>31%</td>
<td>19%</td>
<td>29%</td>
<td>11%</td>
<td>0%</td>
<td>32%</td>
<td>10%</td>
<td>6%</td>
<td>0%</td>
<td>3%</td>
<td>1%</td>
<td>14%</td>
</tr>
<tr>
<td>Ed. &amp; Support Groups (n=173)</td>
<td>40%</td>
<td>26%</td>
<td>46%</td>
<td>17%</td>
<td>1%</td>
<td>36%</td>
<td>6%</td>
<td>4%</td>
<td>0%</td>
<td>5%</td>
<td>7%</td>
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</tr>
<tr>
<td>Counseling (n=145)</td>
<td>41%</td>
<td>24%</td>
<td>56%</td>
<td>21%</td>
<td>3%</td>
<td>29%</td>
<td>3%</td>
<td>2%</td>
<td>1%</td>
<td>3%</td>
<td>6%</td>
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<tr>
<td>Nutritional Counseling (n=124)</td>
<td>42%</td>
<td>18%</td>
<td>60%</td>
<td>12%</td>
<td>1%</td>
<td>29%</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
<td>2%</td>
<td>6%</td>
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<tr>
<td>Pain Management (n=127)</td>
<td>64%</td>
<td>21%</td>
<td>57%</td>
<td>9%</td>
<td>1%</td>
<td>23%</td>
<td>5%</td>
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<td>2%</td>
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<tr>
<td>Alt./ Complement. Medicine (n=68)</td>
<td>21%</td>
<td>29%</td>
<td>32%</td>
<td>7%</td>
<td>3%</td>
<td>28%</td>
<td>16%</td>
<td>13%</td>
<td>0%</td>
<td>7%</td>
<td>9%</td>
<td></td>
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<tr>
<td>Home Care (n=101)</td>
<td>35%</td>
<td>34%</td>
<td>46%</td>
<td>17%</td>
<td>0%</td>
<td>17%</td>
<td>11%</td>
<td>5%</td>
<td>0%</td>
<td>4%</td>
<td>11%</td>
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</tr>
<tr>
<td>Palliative Care (n=62)</td>
<td>39%</td>
<td>18%</td>
<td>50%</td>
<td>11%</td>
<td>0%</td>
<td>24%</td>
<td>7%</td>
<td>3%</td>
<td>0%</td>
<td>7%</td>
<td>11%</td>
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</tr>
<tr>
<td>Hospice (n=177)</td>
<td>24%</td>
<td>53%</td>
<td>31%</td>
<td>15%</td>
<td>7%</td>
<td>28%</td>
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<td>15%</td>
<td>6%</td>
<td>1%</td>
<td>11%</td>
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</table>
Study Limitations

1. The “Yes” results on the 15 services are based on relatively few respondents. On average, about 9% of the entire sample answered yes to the question, “Have you used this service,” for each of the 15 services.

2. Some of the service use categories may have been beyond the comprehension of some respondents. Some completed surveys indicated that some respondents did not understand a particular service or did not understand what the term meant. Definitions of terms were somewhat brief and may not have helped the respondents.

3. Some people wrote down multiple cancer diagnoses. The instructions do not specify whether to list the first and/or subsequent diagnoses. Multiple diagnoses make it difficult to do cross-tabulations.

4. Some respondents were confused about the survey’s skip patterns and the sequence of questions. Some early questions were skipped and then later ones, dependent on the earlier ones, were answered.

5. Many respondents left the latter pages of the survey blank. The length of the survey and the redundancies may have contributed to “survey fatigue.”

6. Many hospitals did not submit a large number of completed surveys. The results may not reflect an adequate understanding of patient needs at various hospitals.

7. Females appear to be over-represented in the study sample, especially at non-ACoS facilities.

8. Some hospitals distributed surveys that were returned unanswered. Some of these surveys were not returned to the Muskie School. Hence we do not have a true sense of the overall number of distributed surveys.

Recommendations

1. More in-depth information is needed to understand why respondents do or do not use certain services. Conducting focus groups, with adequate age and gender representation, at both ACoS and non-ACoS facilities would help uncover some of these reasons.

2. If this or another similar survey is undertaken, a better sampling strategy is needed. Many hospitals returned less than 50% of the surveys allocated to them. Perhaps more time is needed or a different time of the year is better. A better process/criteria for hospitals estimating the number of surveys they can distribute is needed.

3. The differences in responses among ACoS and non-ACoS facilities need further investigation. As Table 5 indicates, a higher percentage of non-ACoS respondents used the 15 rehabilitative and survivorship services.

4. If this survey is repeated, it should be shortened and/or reformatted. Based on the responses (in many cases the lack of responses), respondents did not adequately complete the instrument. If re-piloted, respondents should be questioned about the instruments after completing it.
5. The referral source data in Table 6 point to the need for expanding sources of information for various support services. The results indicate that doctors/physicians are the leading source of information for a variety of services. Given how busy doctors are and the limited time they have with patients, it may be appropriate to explore other ways of conveying support services information to patients.

6. Most questions dealing with the quality of rehabilitation and survivorship services are based on relatively few responses. The data in this report do not adequately address this issue. Further study is warranted.

7. The same as above for payment of services.
American College of Surgeons Commission on Cancer Facilities in Maine

American College of Surgeons Commission on Cancer (ACoS) approved hospitals ensure quality cancer care through the availability of state of the art technology, access to multi-disciplinary consultation and treatment, and ongoing quality assessment that monitors treatment effectiveness and outcomes. Every approved cancer program must provide a host of basic services. These services are provided on-site at the facility, by referral, or are coordinated with other facilities or local agencies. Services include: Diagnostic, Treatment, Pain management, Rehabilitation, Support, Counseling, Hospice care, Nutritional support, Pastoral care, Patient and family support, and Prevention and early detection.

Facilities in Maine

Central Maine Medical Center
Eastern Maine Medical Center
Goodall Hospital
MaineGeneral Medical Center
Maine Medical Center
  o Maine Center Radiation Oncology - Portland
  o MMC Radiation Oncology - Scarborough
  o Coastal Cancer Treatment Center
  o MMC Outpatient IV - Scarborough
Penobscot Bay Medical Center
Redington Fairview General Hospital
Southern Maine Medical Center
Stephens Memorial Hospital
St. Mary's Regional Medical Center
Togus VA Medical Center
Appendix B

Cancer Rehabilitation & Support Services Survey

About the Survey:

The survey focuses on support and rehabilitation services you may have used or needed so far during your cancer treatment, care and/or recovery. The survey is sponsored by the Maine Comprehensive Cancer Control Program/Maine Bureau of Health/Department of Human Services, the Maine Cancer Consortium Rehabilitation and Survivorship Work Group and Eastern Maine Medical Center's Cancer Care of Maine. Whether you are newly diagnosed, actively receiving treatment or here for a follow up appointment, we could use your input. Patients at hospitals throughout the state are being asked to participate. Responses will provide information from people, like you, across Maine about what is needed, used, helpful and how easy it is to access and learn about available services. Your responses will help in statewide planning.

Participation:

Your input is voluntary. By filling out the survey, you are giving your consent to participate. **Completing the survey will not keep you from being on time for your appointment.** After reviewing the survey if you decide you do not want to complete it, simply return it to the box marked **SURVEY RETURN** without filling it out.

Confidentiality:

This is an anonymous survey. Please **do not put your name anywhere.** All responses will be kept confidential and results will be reported in a group format.

**Survey Completion Instructions:**

♦ If you want to participate in the survey, follow the instructions on the next page

♦ Again, if you decide you do not want to complete the survey, please place it in the box marked **SURVEY RETURN** without filling it out.

**Resources:**

For more information related to the survey, contact Anita Ruff at 207-287-5358 or [Anita.Ruff@maine.gov](mailto:Anita.Ruff@maine.gov)
At CancerCare of Maine, if you have questions, ask for Nadine Bullion, LCSW, Support Service Manager or call 973-7476 or 1-800-987-3005 or e-mail [nbullion@emh.org](mailto:nbullion@emh.org)
Service Use Survey Instructions

♦ This survey will take about 10 minutes to complete.

♦ Completing the survey will NOT delay your care.

♦ Please read every question.

♦ On the last page there are two additional questions - numbers 87 & 88, please be sure to answer these too!

Please complete the following:

Age: __________________ Male or Female (circle one)

Year cancer was diagnosed:

Cancer diagnosis:

Are you currently receiving treatment for this cancer?  Yes  No (circle one)
Transportation
(Help with rides or with the cost of getting to your health care.)

1. Have you used this service?
   _ Yes (please skip to question 2)

   _ No (check all that apply)
   ___ I do not have a need for the service.
   ___ The service was not available.
   ___ I could not afford the service.
   ___ I was not aware of the service.
   ___ Other: (please specify):______________

   Have you heard about this service?
   _____Yes (Go to question 2)  _____No (Go to the next page)

If you did not use this service, go to the next page.

2. How did you hear about this service? (check all that apply)
   _ Doctor
   _ Clergy
   _ Telephone help line
   _ Friend/family
   _ Brochure
   _ Web/Internet
   _ Nurse
   _ Newspaper
   _ Other (specify):______________
   _ Social worker
   _ Television

3. Did this service help you?
   _ Yes
   _ No

4. Did this service help your family?
   _ Yes
   _ No

5. Did you use this service within 30 miles of your home?
   _ Yes
   _ No

6. How did you pay for this service (check all that apply)
   _ Health insurance
   _ Service was free
   _ On my own
   _ Other financial support (specify):______________

Please continue to next page™
Lodging
(Help with a place to stay while getting care.)

7. Have you used this service?
   ___ Yes (please skip to question 8)
   ___ No (check all that apply)
   ____ I do not have a need for the service.
   ____ The service was not available.
   ____ I could not afford the service.
   ____ I was not aware of the service.
   ____ Other: (please specify) _______________________

Have you heard about this service?
   ____ Yes (Go to question 8)    ____ No (Go to the next page)

8. How did you hear about this service? (check all that apply)
   ____ Doctor
   ____ Friend/family
   ____ Nurse
   ____ Social worker
   ____ Clergy
   ____ Brochure
   ____ Newspaper
   ____ Television
   ____ Telephone help line
   ____ Web/Internet
   ____ Other (specify): _______________________

9. Did this service help you? (If you did not use this service go to the next page)
   ____ Yes
   ____ No

10. Did this service help your family?
    ____ Yes
    ____ No

11. Did you use this service within 30 miles of your home?
    ____ Yes
    ____ No

12. How did you pay for this service (check all that apply)
    ____ Health insurance
    ____ Service was free
    ____ On my own
    ____ Other financial support (specify): _______________________

Please continue to next page™
Financial Assistance
(Help with finding ways to pay for your care.)

13. Have you used this service?
    ____ Yes (please skip to question 14)
    ____ No (check all that apply)
    ____ I do not have a need for the service.
    ____ The service was not available.
    ____ I could not afford the service.
    ____ I was not aware of the service.
    ____ Other: (please specify)____________________

Have you heard about this service?
    ____ Yes  ____ No
    (Go to question 14)  (Go to the next page)

14. How did you hear about this service? (check all that apply)
    ____ Doctor  ____ Clergy  ____ Telephone help line
    ____ Friend/family  ____ Brochure  ____ Web/Internet
    ____ Nurse  ____ Newspaper  ____ Other (specify):____________________
    ____ Social worker  ____ Television

15. Did this service help you? (If you did not use this service go to the next page)
    ____ Yes  ____ No

16. Did this service help your family?
    ____ Yes  ____ No

17. Did you use this service within 30 miles of your home?
    ____ Yes  ____ No

18. How did you pay for this service (check all that apply)
    ____ Health insurance  ____ Service was free
    ____ On my own  ____ Other financial support (specify):____________________

Please continue to next page
Physical Therapy

(Help with recovery from cancer surgery or treatment.)

19. Have you used this service?  
   ___ Yes (please skip to question 20)  
   ___ No (check all that apply)  
      ____ I do not have a need for the service.  
      ____ The service was not available.  
      ____ I could not afford the service.  
      ____ I was not aware of the service.  
      ____ Other: (please specify) ____________________________

Have you heard about this service?  
   ___ Yes  ___ No  
   (Go to question 20) (Go to the next page)

20. How did you hear about this service? (check all that apply)  
   ___ Doctor  ___ Clergy  ___ Telephone help line  
   ___ Friend/family  ___ Brochure  ___ Web/Internet  
   ___ Nurse  ___ Newspaper  ___ Other (specify): ____________________________  
   ___ Social worker  ___ Television

21. Did this service help you? (If you did not use this service go to the next page)  
   ___ Yes  ___ No

22. Did this service help your family?  
   ___ Yes  ___ No

23. Did you use this service within 30 miles of your home?  
   ___ Yes  ___ No

24. How did you pay for this service (check all that apply)  
   ___ Health insurance  ___ Service was free  
   ___ On my own  ___ Other financial support (specify): ____________________________

Please continue to next page™
Lymphedema
(Help with management of lymphedema.)

25. Have you used this service?
___ Yes (please skip to question 26)
___ No (check all that apply)
   ___ I do not have a need for the service.
   ___ The service was not available.
   ___ I could not afford the service.
   ___ I was not aware of the service.
   ___ Other: ________________________________

Have you heard about this service?
___ Yes (Go to question 26)  ___ No (Go to the next page)

26. How did you hear about this service? (check all that apply)
   ___ Doctor          ___ Clergy   ___ Telephone help line
   ___ Friend/family   ___ Brochure ___ Web/Internet
   ___ Nurse          ___ Newspaper ___ Other (specify): ____________________
   ___ Social worker  ___ Television

27. Did this service help you? (If you did not use this service go to the next page)
   ___ Yes        ___ No

28. Did this service help your family?
   ___ Yes        ___ No

29. Did you use this service within 30 miles of your home?
   ___ Yes        ___ No

30. How did you pay for this service (check all that apply)
   ___ Health insurance ___ Service was free
   ___ On my own       ___ Other financial support (specify): ____________________

Please continue to next page™
31. Have you used this service?  
   ___ Yes (please skip to question 32)  
   ___ No (check all that apply)  

   ____ I do not have a need for the service.  
   ____ The service was not available.  
   ____ I could not afford the service.  
   ____ I was not aware of the service.  
   ____ Other: (please specify)__________________________

Have you heard about this service?  
   ____ Yes  
   ____ No  
   (Go to question 32)  
   (Go to the next page)

32. How did you hear about this service? (check all that apply)  

   ___ Doctor  
   ___ Clergy  
   ___ Telephone help line  
   ___ Friend/family  
   ___ Brochure  
   ___ Web/Internet  
   ___ Nurse  
   ___ Newspaper  
   ___ Other (specify):__________________________  
   ___ Social worker  
   ___ Television

33. Did this service help you? (If you did not use this service go to the next page)  

   ___ Yes  
   ___ No

34. Did this service help your family?  

   ___ Yes  
   ___ No

35. Did you use this service within 30 miles of your home?  

   ___ Yes  
   ___ No

36. How did you pay for this service (check all that apply)  

   ___ Health insurance  
   ___ Service was free  
   ___ On my own  
   ___ Other financial support (specify):__________________________

Please continue to next page™
37. Have you used this service?
   _ Yes  (please skip to question 38)  _ No  (check all that apply)
   _ I do not have a need for the service.
   _ The service was not available.
   _ I could not afford the service.
   _ I was not aware of the service.
   _ Other: (please specify)________________________

38. How did you hear about this service? (check all that apply)
   _ Doctor  _ Clergy  _ Telephone help line
   _ Friend/family  _ Brochure  _ Web/Internet
   _ Nurse  _ Newspaper  _ Other (specify):________________________
   _ Social worker  _ Television

39. Did this service help you? (If you did not use this service go to the next page)
   _ Yes  _ No

40. Did this service help your family?
   _ Yes  _ No

41. Did you use this service within 30 miles of your home?
   _ Yes  _ No

42. How did you pay for this service (check all that apply)
   _ Health insurance  _ Service was free
   _ On my own  _ Other financial support (specify):____________________

Please continue to next page™
Educational & Support Groups
(Help with learning more about your cancer & gaining support.)

43. Have you used this service?  
   __ Yes (please skip to question 44)  
   ___ No (check all that apply)  
      ___ I do not have a need for the service.  
      ___ The service was not available.  
      ___ I could not afford the service.  
      ___ I was not aware of the service.  
      ___ Other: (please specify)_________________

Have you heard about this service?  
   ___ Yes (Go to question 44)  
   ___ No (Go to the next page)

44. How did you hear about this service? (check all that apply)  
   ___ Doctor  
   ___ Friend/family  
   ___ Nurse  
   ___ Social worker  
   ___ Clergy  
   ___ Brochure  
   ___ Telephone help line  
   ___ Newspaper  
   ___ Web/Internet  
   ___ Other (specify):

45. Did this service help you? (If you did not use this service go to the next page)  
   ___ Yes  
   ___ No

46. Did this service help your family?  
   ___ Yes  
   ___ No

47. Did you use this service within 30 miles of your home?  
   ___ Yes  
   ___ No

48. How did you pay for this service (check all that apply)  
   ___ Health insurance  
   ___ Service was free  
   ___ On my own  
   ___ Other financial support (specify):_________________

Please continue to next page™
Counseling

(Help with coping with diagnosis, treatment and recovery.)

49. Have you used this service?
   __ Yes (please skip to question 50) __ No (check all that apply)
       _____ I do not have a need for the service.
       _____ The service was not available.
       _____ I could not afford the service.
       _____ I was not aware of the service.
       _____ Other: (please specify) ________________________________

Have you heard about this service?
_____ Yes (Go to question 50) ______ No (Go to the next page)

50. How did you hear about this service? (Check all that apply)
    __ Doctor        __ Clergy        __ Telephone help line
    __ Friend/family __ Brochure      __ Web/Internet
    __ Nurse         __ Newspaper     __ Other (specify): __________________________
    __ Social worker __ Television

51. Did this service help you? (If you did not use this service go to the next page)
    __ Yes        __ No

52. Did this service help your family?
    __ Yes        __ No

53. Did you use this service within 30 miles of your home?
    __ Yes        __ No

54. How did you pay for this service (check all that apply)
    __ Health insurance __ Service was free
    __ On my own       __ Other financial support (specify): _______________________

Please continue to next page™
55. Have you used this service? __ Yes (please skip to question 56)

___ No (check all that apply)
   ___ I do not have a need for the service.
   ___ The service was not available.
   ___ I could not afford the service.
   ___ I was not aware of the service.
   ___ Other: (please specify) ________________

Have you heard about this service?
   ____ Yes  ___ No
   (Go to question 56) (Go to the next page)

56. How did you hear about this service? (check all that apply)
    __ Doctor  ___ Clergy  ___ Telephone help line
    ___ Friend/family  ___ Brochure  ___ Web/Internet
    ___ Nurse  ___ Newspaper  ___ Other (specify): ______________
    ___ Social worker  ___ Television

57. Did this service help you? (If you did not use this service go to the next page)
    __ Yes  ___ No

58. Did this service help your family?
    __ Yes  ___ No

59. Did you use this service within 30 miles of your home?
    __ Yes  ___ No

60. How did you pay for this service (check all that apply)
    __ Health insurance  ___ Service was free
    ___ On my own  ___ Other financial support (specify): ______________

Please continue to next page™
Pain Management
(Help with coping with pain related to cancer diagnosis.)

61. Have you used this service?
   ____ Yes (please skip to question 62)
   ____ No (check all that apply)
       ____ I do not have a need for the service.
       ____ The service was not available.
       ____ I could not afford the service.
       ____ I was not aware of the service.
       ____ Other: (please specify) ______________________

Have you heard about this service?
   ____ Yes (Go to question 60)        ____ No (Go to the next page)

62. How did you hear about this service? (check all that apply)
    ____ Doctor        ____ Clergy        ____ Telephone help line
    ____ Friend/family  ____ Brochure       ____ Web/Internet
    ____ Nurse         ____ Newspaper       ____ Other (specify): ______________________
    ____ Social worker  ____ Television

63. Did this service help you? (If you did not use this service go to the next page)
    ____ Yes        ____ No

64. Did this service help your family?
    ____ Yes        ____ No

65. Did you use this service within 30 miles of your home?
    ____ Yes        ____ No

66. How did you pay for this service (check all that apply)
    ____ Health insurance ____ Service was free
    ____ On my own        ____ Other financial support (specify): ______________________

Please continue to next page™
Alternative/Complementary Medicine
(Included but not limited to, herbal medicine, acupuncture, Reiki, homeopathy & massage)

67. Have you used this service?
   __ Yes (please skip to question 68)
   ____ No (check all that apply)
   ____ I do not have a need for the service.
   ____ The service was not available.
   ____ I could not afford the service.
   ____ I was not aware of the service.
   ____ Other: (please specify)

Have you heard about this service?
   ____ Yes  (Go to question 64)  ____ No  (Go to the next page)

68. How did you hear about this service? (check all that apply)
   ___ Doctor
   ___ Clergy
   ___ Telephone help line
   ___ Friend/family
   ___ Brochure
   ___ Web/Internet
   ___ Nurse
   ___ Newspaper
   ___ Other (specify): ____________________
   ___ Social worker
   ___ Television

69. Did this service help you? (If you did not use this service go to the next page)
   ___ Yes  ___ No

70. Did this service help your family?
   ___ Yes  ___ No

71. Did you use this service within 30 miles of your home?
   ___ Yes  ___ No

72. How did you pay for this service (check all that apply)
   ___ Health insurance  ___ Service was free
   ___ On my own  ___ Other financial support (specify): ____________________

Please continue to next page™
Home Care
(Help with chemo therapy infusion at home or other healthcare at home.)

73. Have you used this service?
   __ Yes (please skip to question 74)

   ____ No (check all that apply)
   ____ I do not have a need for the service.
   ____ The service was not available.
   ____ I could not afford the service.
   ____ I was not aware of the service.
   ____ Other: (please specify) __________________________

Have you heard about this service?
   ____ Yes (Go to question 70)
   ____ No (Go to the next page)

74. How did you hear about this service? (check all that apply)
   __ Doctor  __ Clergy  __ Telephone help line
   __ Friend/family  __ Brochure  __ Web/Internet
   __ Nurse  __ Newspaper  __ Other (specify): __________________________
   __ Social worker  __ Television

75. Did this service help you? (If you did not use this service go to the next page)
   __ Yes  __ No

76. Did this service help your family?
   __ Yes  __ No

77. Did you use this service within 30 miles of your home?
   __ Yes  __ No

78. How did you pay for this service (check all that apply)
   __ Health insurance  __ Service was free
   __ On my own  __ Other financial support (specify): __________________________

Please continue to next page™
Palliative Care

(Help with management of a range of symptoms related to a cancer diagnosis.)

79. Have you used this service? __ Yes (please skip to question 80)

   ___ No (check all that apply)
   ___ I do not have a need for the service.
   ___ The service was not available.
   ___ I could not afford the service.
   ___ I was not aware of the service.
   ___ Other: (please specify) __________________________

80. How did you hear about this service? (check all that apply)

   ___ Doctor       ___ Clergy       ___ Telephone help line
   ___ Friend/family ___ Brochure      ___ Web/Internet
   ___ Nurse        ___ Newspaper     ___ Other (specify):__________________
   ___ Social worker ___ Television    ________________________

81. Did this service help you? (If you did not use this service go to the next page)

   ___ Yes     ___ No

82. Did this service help your family?

   ___ Yes     ___ No

83. Did you use this service within 30 miles of your home?

   ___ Yes     ___ No

84. How did you pay for this service (check all that apply)

   ___ Health insurance    ___ Service was free
   ___ On my own           ___ Other financial support (specify):______________

Please continue to next page™
Hospice Care

(Help coping with a limited life expectancy - may include volunteer support and/or a range of in home services.)

85. Have you used this service?
   ___ Yes (please skip to question 86)

   ___ No (check all that apply)
   ____ I do not have a need for the service.
   ____ The service was not available.
   ____ I could not afford the service.
   ____ I was not aware of the service.
   ____ Other: (please specify)_________________

86. How did you hear about this service? (check all that apply)
   ___ Doctor
   ___ Clergy
   ___ Telephone help line
   ___ Friend/family
   ___ Brochure
   ___ Web/Internet
   ___ Nurse
   ___ Newspaper
   ___ Other (specify):_________________
   ___ Social worker
   ___ Television

87. Did this service help you? (If you did not use this service, go to question 87)
   ___ Yes
   ___ No

88. Did this service help your family?
   ___ Yes
   ___ No

89. Did you use this service within 30 miles of your home?
   ___ Yes
   ___ No

90. How did you pay for this service (check all that apply)
   ___ Health insurance
   ___ Service was free
   ___ On my own
   ___ Other financial support (specify):_________________

91. Was this survey easy to complete? ______Yes ______ No

92. How many minutes did it take you to complete? ______

Thank you very much for your time & help!
Appendix C

Maine Cancer Consortium’s Rehabilitation and Survivorship Work Group

Michaele Bailey
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### Appendix D

**Responses by Hospital**

Hospitals are not identified by Name or Code. They have been assigned a random number in this chart.

<table>
<thead>
<tr>
<th>Number</th>
<th># of Returned Responses</th>
<th>% Returned</th>
<th># Distributed</th>
<th>% Returned/Distributed</th>
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<tr>
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<td>39.9%</td>
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<table>
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<tr>
<th>Type</th>
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<th>% Returned</th>
<th># Distributed</th>
<th>% Returned/Distributed</th>
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<tbody>
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<td>ACoS facilities</td>
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<td>1,500</td>
<td>45.1%</td>
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<tr>
<td>Non-ACoS facilities</td>
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<td>21.5%</td>
<td>660</td>
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