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

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The author is on the staff of the
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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.

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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.¹

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?
• 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>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-39*</td>
<td>29</td>
</tr>
<tr>
<td>40-49</td>
<td>98</td>
</tr>
<tr>
<td>50-59</td>
<td>207</td>
</tr>
<tr>
<td>60-69</td>
<td>228</td>
</tr>
<tr>
<td>70-79</td>
<td>190</td>
</tr>
<tr>
<td>80-89</td>
<td>91</td>
</tr>
<tr>
<td>Total</td>
<td>843</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>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>
</tr>
<tr>
<td>Male</td>
<td>36.4%</td>
<td>38.8%</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%).

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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**

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>31.6%</td>
</tr>
<tr>
<td>Leukemia/Lymphoma/Myeloma</td>
<td>15.6%</td>
</tr>
<tr>
<td>Prostate/Testicular</td>
<td>10.7%</td>
</tr>
<tr>
<td>Lung</td>
<td>10.5%</td>
</tr>
<tr>
<td>Colon/Rectum/Anus/Gastro</td>
<td>9.0%</td>
</tr>
<tr>
<td>Head &amp; Neck/Thyroid/Eosoph</td>
<td>8.4%</td>
</tr>
<tr>
<td>Gyn</td>
<td>2.9%</td>
</tr>
<tr>
<td>Skin</td>
<td>2.4%</td>
</tr>
<tr>
<td>Parathyroid/Thyroid/Liver</td>
<td>1.7%</td>
</tr>
<tr>
<td>Kidney/Bladder</td>
<td>1.2%</td>
</tr>
<tr>
<td>Breast/Other</td>
<td>0.7%</td>
</tr>
<tr>
<td>Other</td>
<td>3.3%</td>
</tr>
</tbody>
</table>

**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. 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 3. Age at Diagnosis and Length of Time (in years) with Diagnosis**

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age at Diagnosis (n=802)</td>
<td>59.5</td>
</tr>
<tr>
<td>Mean Length of Time with Cancer Diagnosis</td>
<td>3.1</td>
</tr>
<tr>
<td>Length of Time with Cancer Diagnosis (range)</td>
<td>0 to 51 years</td>
</tr>
<tr>
<td>Year of Diagnosis</td>
<td>1953 to present</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>8.9%</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. *The Non-Response Rate 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

| Transportation (n=82) | 54% | 27% | 16% | 18% | 0% | 5% | 1% | 1% | 0% | 0% | 9% |
| Lodging (n=55)       | 46% | 26% | 16% | 18% | 0% | 4% | 0% | 2% | 2% | 0% | 4% |
| Financial Assistance (n=84) | 41% | 23% | 24% | 37% | 1% | 5% | 0% | 1% | 0% | 1% | 12% |
| Physical Therapy (n=88) | 82% | 10% | 34% | 23% | 1% | 5% | 0% | 0% | 0% | 0% | 1% | 2% |
| Lymphedema (n=41)    | 90% | 7%  | 24% | 5%  | 0% | 2% | 0% | 0% | 0% | 0% | 2% |
| Occupational Therapy (n=48) | 71% | 15% | 35% | 38% | 2% | 4% | 2% | 0% | 0% | 0% | 4% |
| Speech Therapy (n=19) | 84% | 26% | 21% | 26% | 5% | 0% | 0% | 0% | 0% | 0% | 0% |
| Ed. & Support Groups (n=122) | 57% | 25% | 50% | 30% | 2% | 18% | 4% | 1% | 2% | 6% | 7% |
| Counseling (n=77)    | 68% | 20% | 35% | 42% | 8% | 7% | 0% | 0% | 0% | 4% | 4% |
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.

Services most likely to be free were education and support groups (74%) and financial assistance (50%). Services least likely to be free were home care (4%), occupational therapy (7%), and physical therapy (8%).

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 Domain</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>
<thead>
<tr>
<th>Service</th>
<th>Doctor</th>
<th>Family/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>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>
</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>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>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>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>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>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>
</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>
</tr>
<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>
</tr>
<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>
<td>4%</td>
<td>0%</td>
<td>2%</td>
<td>6%</td>
</tr>
<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>
</tr>
<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>
</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>
</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>
<td>20%</td>
<td>15%</td>
<td>6%</td>
<td>1%</td>
<td>11%</td>
</tr>
</tbody>
</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.
Appendix A

American College of Surgeons (ACoS) 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
  - Maine Center Radiation Oncology - Portland
  - MMC Radiation Oncology -Scarborough
  - Coastal Cancer Treatment Center
  - 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 CancerCare 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 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
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 __ No
(Go to question 2) (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 ________________________

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

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

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 (Go to question 14) ___ No (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:  (please specify)__________________

   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 ➔
Occupational Therapy
(Help with recovery related to cancer diagnosis.)

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 (Go to question 32)  ___ No (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 ➔
Speech Therapy
(Help with recovery from cancer diagnosis or care.)

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
   ___ Other (specify): _______________________

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

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

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
Nutritional Counseling

(Help with nutritional needs.)

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  _____ No
   (Go to question 60)  (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  
____ Other (specify): ________________________

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  
   (Go to question 76)  
   (Go to the next page)

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) ______________________

Have you heard about this service?
   _ Yes (Go to question 82)
   _ No (Go to question 87)

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
UMO Social Work Intern

Terry Baker
American Cancer Society

Nadine Bullion, LCSW
CancerCare of Maine

Paulette Burbank
New England Rehabilitation Hospital

Doug Dieckmann
American Cancer Society

Melanie Feinburg
Maine Medical Center

Brenda Joly, PhD
Maine Center for Public Health

Diane Mulkhey
Central Maine Medical Center

Michael Reesman
Beth C. Wright Cancer Resource Center

Holly Richards
Maine Comprehensive Cancer Control Program

Anita Ruff
Maine Comprehensive Cancer Control Program

Ellen Sharp
UMO Social Work Intern

Cheryl Tucker
American Cancer Society
## Appendix D

### Responses by Hospital

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

<table>
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<td>17</td>
<td>2.0%</td>
<td>35</td>
<td>48.6%</td>
</tr>
<tr>
<td>19</td>
<td>30</td>
<td>3.5%</td>
<td>75</td>
<td>40.0%</td>
</tr>
<tr>
<td>20</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>21</td>
<td>1</td>
<td>0.1%</td>
<td>20</td>
<td>5.0%</td>
</tr>
<tr>
<td>22</td>
<td>28</td>
<td>3.3%</td>
<td>40</td>
<td>70.0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>861</strong></td>
<td><strong>100.0%</strong></td>
<td><strong>2,160</strong></td>
<td><strong>39.9%</strong></td>
</tr>
</tbody>
</table>

| ACoS facilities | 676 | 78.5% | 1,500 | 45.1% |
| Non-ACoS facilities | 185 | 21.5% | 660 | 28.0% |
List of Hospitals Participating in the Survey

1. Blue Hill Memorial
2. Central Maine Medical Center
3. Eastern Maine Medical Center
4. Franklin Memorial
5. Goodall Hospital
6. Maine Coast Memorial
7. Maine General Medical Center
8. Maine Center for Cancer Care
9. Maine Medical Center Radiation Oncology, Portland
10. Coastal Cancer Treatment Center
11. Mayo Regional Hospital
12. Millinocket Regional Hospital
13. Mount Desert Island Hospital
14. Northern Maine Medical Center
15. Penobscot Bay Medical Center
16. Redington Fairview General Hospital
17. St. Mary's Regional Medical Center
18. Waldo County Hospital
19. York Hospital