



Cancer Services of New Mexico

Providing Services to Reduce Cancer Suffering for New Mexico's Families

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New Mexico Cancer Services Survey

*A statewide survey to understand gaps in New Mexico's
cancer-related services, from the perspective of cancer
patients/survivors and their loved ones*

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Final Report

March, 2011



Contents

Contents..... 1

Acknowledgements..... 3

Executive Summary..... 5

Background..... 7

Why Did New Mexico Need a Cancer Services Survey?

Objectives of the New Mexico Cancer Services Survey

About Cancer Services of New Mexico..... 9

1. Study Approach..... 11

Survey Instrument

Data Collection Approach

Data Analysis Approach

Limitations of the Approach

2. Respondent Demographics..... 13

Respondent Relationship to the Cancer Patient/Survivor

Breakdown by Treatment Status

Breakdown by Diagnosis Date

Breakdown by Type of Cancer

Breakdown by Patient's Gender

Breakdown by Patient's Age at Diagnosis

Breakdown by Patient's Ethnic/Racial Group

Breakdown by Patient's Insurance Coverage During Treatment

Breakdown by Patient's Residence Location

3. Importance of Different Cancer-Related Services..... 25

4. Satisfaction with New Mexico’s Cancer-Related Services.....	27
5. Perceived Gaps in New Mexico’s Cancer-Related Services.....	31
<i>Calculation of “Gap Ratings”</i>	
<i>Gaps in Ease of Access and Service Quality</i>	
6. Sources of Information for Patients/Survivors and Their Loved Ones... 	37
7. Satisfaction with Coordination/Communication Between Providers.....	39
8. Differences Among Demographic Groups.....	41
<i>Comparisons by Respondent Type</i>	
<i>Comparisons by Treatment Status</i>	
<i>Comparisons by Year of Most Recent Diagnosis</i>	
<i>Comparisons by Tumor Type</i>	
<i>Comparisons by Patient’s Gender</i>	
<i>Comparisons by Patient’s Age at Diagnosis</i>	
<i>Comparisons by Patient’s Ethnic/Racial Group</i>	
<i>Comparisons by Patient’s Insurance Type During Treatment</i>	
<i>Comparisons by Patient’s Region of Residence</i>	
9. Comparisons to the 2002-2004 NM Cancer Services Survey.....	67
<i>Differences Between the 2002-2004 and 2010-2011 Surveys</i>	
<i>Comparison of Results from the 2002-2004 and 2010-2011 Surveys</i>	
10. Discussion.....	69
<i>Key Findings and Implications</i>	
<i>Next Steps</i>	
Appendices.....	71
• <i>Appendix A: Survey Questionnaire</i>	
• <i>Appendix B: Comments on Services Where Respondents Reported Low or Moderate Satisfaction</i>	
• <i>Appendix C: Comments on Factors Limiting Access to Needed Services</i>	
• <i>Appendix D: Comments on Services that Did Not Exist to Support Respondents</i>	
• <i>Appendix E: Comments on Services that Respondents Would Like to See Improved</i>	
• <i>Appendix F: Comments on Coordination/Communication Between Providers</i>	
• <i>Appendix G: Additional Comments</i>	



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An amazing team of volunteers surveyed the cancer patients/survivors and loved ones who participated in this project. Special thanks go to Elizabeth Jaramillo-Dalton, who spent countless hours coordinating this process and personally conducted hundreds of surveys. Elizabeth’s dedication and commitment to this project were remarkable – we couldn’t have done it without her. Thanks as well to the rest of our survey team – Menolda Bakker, Lisa Briggs-Valdez, Patricia Busse, Mike Capeless, Lynda Cook, Juanita Lobato, and Neil and Carole Mathis – for the warmth and compassion they showed during the many hours spent talking to survey participants about their cancer journeys. And, an extra thank you to Lisa Briggs-Valdez, who handled much of the data entry for the project.

Oncology clinics across New Mexico generously invited our team to spend time in their clinics collecting data from patients/survivors and their loved ones. Thanks go to the Cancer Institute of New Mexico, CHRISTUS St. Vincent Cancer Center, Hematology-Oncology Associates, Los Alamos Cancer Center, Lovelace Oncology, MD Anderson Radiation Treatment Center at Presbyterian, Memorial Ikard Cancer Treatment Center, MMC Cancer Center, New Hope Cancer Center, New Mexico Cancer Center, Northern NM Cancer Center, Presbyterian Oncology, San Juan Oncology, SW Gynecologic Oncology Associates, and the UNM Cancer Center for their support.

Chuck Wiggins, PhD, and Charles Key, MD, PhD, of the New Mexico Tumor Registry provided valuable insights regarding questionnaire design, sampling approach, and many other aspects of the study. We thank them for reviewing early versions of the survey questionnaire and providing suggestions for improving it. In addition, Dr. Wiggins shared key data that enabled us to see how the demographics of our participants mapped to overall cancer incidence in New Mexico.

Several people reviewed a preliminary draft of this report and offered suggestions for improving the final product. Thanks to Roger Eldridge, Judith Harris, Beth Pinkerton, and Susan Simons for their close review and insightful comments.

Cancer Services of New Mexico’s Board of Directors provides outstanding support and guidance for all aspects of our organization. John Trotter, PhD, offered tremendous assistance with budgeting, survey design, and setting up the initial clinic visits for this effort. Other board members who helped shape this project include Carl Bancroft, Ruth Ann Castellano-Piatt, Gary Eisenberg, Judith Harris, MSN, RN, Kathleen Kreider, Richard Larson, MD, PhD, and Janet Quintana-Cook.

Our deepest thanks go out to everyone who supported this effort!

Blaire Larson
President
Cancer Services of New Mexico

Executive Summary

Cancer Services of New Mexico conducted the New Mexico Cancer Services Survey to understand gaps in New Mexico’s cancer-related services, from the perspective of adult cancer patients/survivors and their loved ones. This study is a follow-up to a similar effort that we conducted in 2002-2004. Our hope is that this report will provide insights that help New Mexico’s cancer services providers customize their offerings to better meet the needs of New Mexicans coping with cancer.

Five hundred and thirty-three (533) New Mexicans coping with cancer were surveyed in 19 different oncology clinic locations throughout New Mexico between January, 2010, and January, 2011. Survey respondents included cancer patients/survivors and their loved ones.

Several analyses were conducted to understand the demographic breakdown of respondents and to compare these demographics to those of all New Mexicans coping with cancer. Our respondents represented a wide variety of tumor types, disease stages, geographic locations, ages, levels of insurance coverage, and ethnic/racial groups. A few groups were somewhat over-represented in the study, including breast cancer patients/survivors; leukemia/lymphoma patients/survivors; women; and residents of Northwestern New Mexico. Other groups were somewhat under-represented in the study, including prostate cancer patients/survivors; those diagnosed at age 75 or older; and residents of Eastern New Mexico. Since we observed relatively few differences in responses across different demographic groups we believe the findings reflected in this report provide a good overall representation of the perspectives of New Mexico’s cancer patients/survivors and their loved ones.

Analyses were conducted to understand the relative importance of a variety of cancer-related services, to understand respondents’ satisfaction with ease of access to, and quality of, each of these services, and to uncover gaps between respondents’ importance ratings and satisfaction ratings for each service. Additional analyses were conducted to understand how patients/survivors and their loved ones get information on managing the disease process, and on how satisfied they are with communication/coordination between their cancer care providers. Highlights of our findings include:

- **Medically-oriented services** (traditional medical treatments such as chemotherapy, radiation, and surgery; early detection/screening services) **were the most important services to respondents**, followed by informational/educational services (information regarding cancer-related services in New Mexico; education on managing the cancer process), and pain management/palliative care.
- Respondents were quite satisfied with ease of access and service quality for the two services rated as most important - traditional medical treatments and early detection/screening. However, **there is substantial opportunity to improve New Mexicans’ experiences** with several other cancer-related services.
 - Services where respondents indicated the **lowest satisfaction with ease of access** included: financial assistance for non-medical expenses; assistance with legal issues; transportation services to/from medical appointments;

complementary/alternative therapies; and emotional support programs for caregivers/family members

- Services where respondents indicated the **lowest satisfaction with service quality** included: assistance with legal issues; financial assistance for non-medical expenses; complementary/alternative therapies; transportation services to/from medical appointments; and in-home care
- For each of the seventeen cancer-related services evaluated, respondents indicated a gap between the importance of the service and their satisfaction with both ease of access to the service and the quality of the service. **Services with the largest gaps may indicate the greatest opportunities for improvement.** These include financial assistance for medical and non-medical expenses; transportation services to/from medical appointments; assistance with legal issues; emotional support programs for caregivers/family members; and information regarding cancer-related services in New Mexico.
- It appears that **patients/survivors and their loved ones are having more difficulty accessing needed services now than they did during our earlier study.** In the 2002-2004 study, 56% of respondents indicated that they did not have difficulty accessing services that they needed. In the current study, only 39% indicated that they did not have difficulty accessing needed services.
- There appear to be substantial **opportunities to improve the way information is disseminated about New Mexico's existing cancer-related services.** Nearly 40% of respondents indicated they were unable to access needed services because they did not know that services were available. Respondents indicated that nurses and physicians were the most helpful sources for providing information on what cancer-related services were available to assist them.
- Over 80% of **respondents indicated that they were satisfied or very satisfied with the level of communication/coordination between their different medical providers** (oncologists, surgeons, primary care providers, etc.). Areas for improvement included coordination between oncologists and primary care providers, and between oncologists and surgeons.
- There are **opportunities to refine service offerings to better meet the needs of specific underserved groups.** For example, patients aged 75 and over reported more challenges related to transportation to/from medical appointments than other respondents, and Southern New Mexicans reported a bigger gap in emotional support services than those in other parts of the state.

This report is being distributed to cancer services providers throughout New Mexico, in the hope that our findings will provide some guidance regarding how they might continue to improve the services offered to New Mexicans coping with cancer. It will also serve as a major input to Cancer Services of New Mexico's strategic planning process, to ensure our programs and services continue to be focused on the areas of greatest need.

There are many additional ways that we could mine the data in our survey database, and we would welcome the opportunity to work with other groups to help them answer specific questions not covered in this report. Please contact us at (505) 259-9583 or info@CancerServicesNM.org if you are interested in learning more.



Background

Why Did New Mexico Need a Cancer Services Survey?

Over 75,000 New Mexicans are currently living with cancer, and over 8,000 more are diagnosed each year. While many are satisfied with the care they receive, stories abound about the frustrations and difficulty that cancer patients and their loved ones face in gaining access to the services and support they need.

In 2001, Cancer Services of New Mexico conducted over 25 interviews with representatives from a wide range of organizations and agencies (including the NM Department of Health, the Indian Health Service, the American Cancer Society, the UNM Cancer Center, and representatives from a variety of hospitals and other service providers) to get their perspectives on current gaps in cancer-related services in New Mexico. One important finding was that **there had never been an in-depth effort to ask New Mexico's cancer patients/survivors and their loved ones how cancer-related services should be modified or improved to better meet their needs.** While there had been limited attempts to understand patient perspectives (e.g., focus groups to support development of the state's cancer plan, small-scale surveys conducted by individual oncology groups), no one had invested the time and effort to undertake a comprehensive study of needs. Yet, this perspective is critical to ensure the appropriate set of cancer-related programs and services are available in our state. **A clear understanding of needs is necessary to optimize the allocation of state, federal, and private funds for cancer care in New Mexico.**

Cancer Services of New Mexico conducted our first NM Cancer Services Survey in 2002-2004, and received tremendous encouragement from New Mexico's cancer services community about the value of this project. Since a substantial amount of time had elapsed since the first survey, in late 2009 we decided to conduct a follow-up effort to generate more timely data for future decision-making.

Objectives of the New Mexico Cancer Services Survey

Our objective in surveying New Mexicans coping with cancer was **to understand people's experiences with New Mexico's cancer services and identify needs that are not being adequately met.**

Survey findings will be used to guide development of Cancer Services of New Mexico's future programs. In addition, we are distributing this report to cancer services providers across the state, to assist them in improving their services. Our intended results are that:

- New Mexico's cancer services providers will be able to allocate their resources more effectively toward needed services; and
- New Mexican cancer patients/survivors and their loved ones will have significantly better experiences during the treatment and survival process.

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About Cancer Services of New Mexico

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Cancer Services of New Mexico is an independent, non-profit, 501(c)(3) organization that provides services to reduce cancer suffering for New Mexico's families. Formed in 2001, we focus on addressing needs that are not met by other organizations. We work closely with other cancer services providers to ensure coordination and avoid duplication of effort. We are the **only** non-profit organization that looks broadly at addressing gaps in cancer-related services, while maintaining a 100% focus on New Mexico.

We serve over 1,500 New Mexicans coping with cancer each year, yet have no full-time staff and no physical office. Programs are developed and led by 300+ volunteers, supported by part-time program managers. As a result, our administrative expenses are less than 5% of revenues.

In addition to the New Mexico Cancer Services Survey, current programs include:

- **Family Cancer Retreats** – twice each year, these free, three-day educational retreats provide New Mexico's adult cancer patients/survivors and their loved ones with tools and information to manage the treatment and survival process. Each program combines in-depth educational workshops with fun family activities. This is the largest general cancer education program in New Mexico and the largest program of its type in the U.S.
- **Legal, Insurance & Paperwork Assistance (LIPA) Program** – free clinics and tools (including a dedicated website – www.NMCancerHelp.org) to help patients/survivors and their loved ones manage the complex set of legal, insurance and paperwork issues associated with a cancer diagnosis.
- **Family Cancer Resource Bags** – statewide distribution of free information kits that help newly diagnosed parents and their children aged 3-18 cope with the impact of cancer on the family.
- **Zoo Day for Kids with Cancer** – a free day of fun, sharing, and learning held each year for New Mexico's pediatric cancer patients/survivors and their families.

For more information on our organization or our programs, please contact:

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1. Study Approach

Survey Instrument

We developed a two-page questionnaire to collect information from New Mexican cancer patients/survivors and their loved ones on their experiences with cancer and cancer-related services in New Mexico. A preliminary version of the questionnaire was tested with a small group of cancer patients/survivors and refined to better capture the perspectives of the target audience.

The questionnaire was available in English- and Spanish-language versions. A copy of the English-language version of the questionnaire is included in Appendix A of this report.

Data Collection Approach

A major challenge in conducting this study involved determining how to get a large, representative group of New Mexico's cancer patients/survivors and their loved ones to share their experiences with us cost-effectively and in a reasonable timeframe.

To address this challenge, we leveraged our strong relationships with New Mexico's oncology community and our statewide network of volunteers, conducting on-site surveys in oncology clinics throughout the state. Surveys were conducted in 19 clinic locations between January, 2010, and January, 2011:

- Cancer Institute of New Mexico – Las Vegas, Santa Fe & Taos
- CHRISTUS St. Vincent Cancer Center – Santa Fe
- Hematology-Oncology Associates – Albuquerque
- Los Alamos Cancer Center – Los Alamos
- Lovelace Oncology – Albuquerque
- MD Anderson Radiation Treatment Center at Presbyterian – Albuquerque
- Memorial Ikard Cancer Treatment Center – Las Cruces
- MMC Cancer Center – Las Cruces
- New Hope Cancer Center – Las Cruces
- New Mexico Cancer Center – Albuquerque, Gallup & Silver City
- Northern NM Cancer Center – Los Alamos
- Presbyterian Oncology – Albuquerque
- San Juan Oncology – Farmington
- SW Gynecologic Oncology Associates – Albuquerque
- UNM Cancer Center – Albuquerque

When patients/survivors and their loved ones arrived at the clinic for their appointments, they were given a flyer explaining that Cancer Services of New Mexico was in the clinic that day conducting a survey. Cancer Services of New Mexico volunteers approached prospective participants in clinic waiting areas, asked them if one person in their group would be willing to take a few minutes to complete the survey questionnaire, and reviewed the survey process with

them. Respondents could choose to fill out the survey questionnaire themselves or be interviewed by the volunteer. Throughout the study, we took significant precautions to ensure patient confidentiality; survey participants were never asked to provide their names or contact information.

A total of five hundred and thirty-three (533) questionnaires were completed as part of the New Mexico Cancer Services Survey.

Data Analysis Approach

Survey responses were analyzed using STATPAC statistical software, running on a desktop PC. Responses were analyzed to understand a variety of respondent perspectives, including the relative importance of various cancer-related services, satisfaction with ease of access to these services, and satisfaction with the quality of these services.

Limitations of the Approach

The population targeted through the New Mexico Cancer Services Survey was not a randomized sample of New Mexicans coping with cancer. This was due to two major factors: a desire to maximize patient confidentiality, and the need to conduct the program within a relatively modest budget. Our sampling approach was designed to generate a pool of respondents whose demographics closely matched that of the entire New Mexican population coping with cancer, and we were relatively successful in meeting this goal. Our respondents represented a wide variety of tumor types, disease stages, geographic locations, ages, levels of insurance coverage, and ethnic/racial groups.

A few groups were somewhat over-represented in the study, including breast cancer patients/survivors; leukemia/lymphoma patients/survivors; women; and residents of Northwestern New Mexico. Other groups are somewhat under-represented in the study, including prostate cancer patients/survivors; those diagnosed at age 75 or older; and residents of Eastern New Mexico. More details on the demographics of the survey respondents are included in Section 2.

Section 8 notes differences that we observed in responses based on a variety of demographic criteria. Since, in most cases, these differences are relatively small, we believe the findings reflected in this report provide a good overall representation of the perspectives of New Mexico's cancer patients/survivors and their loved ones.



2. Respondent Demographics

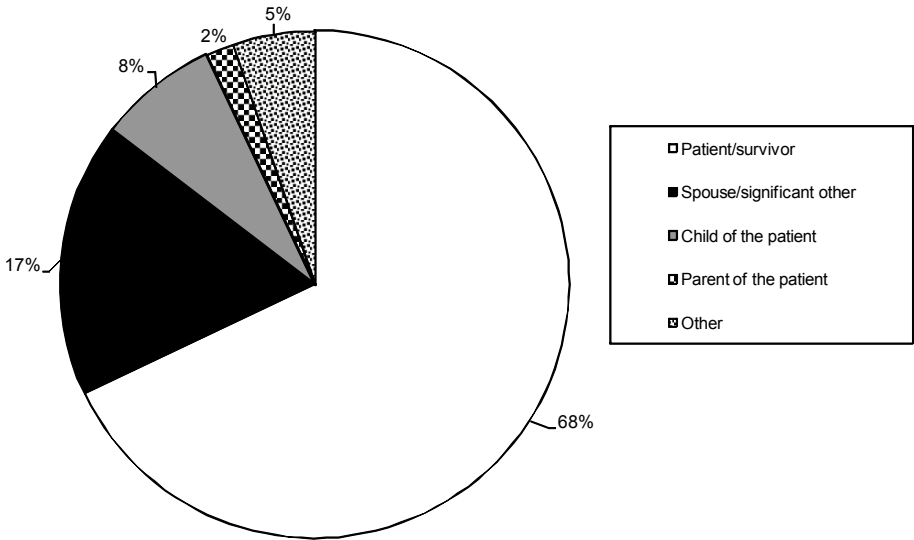
Several analyses were conducted to understand the demographic breakdown of respondents and compare respondent demographics to those of all New Mexicans coping with cancer.

This section summarizes information from participants who provided answers to the demographic questions on the survey. Where possible, we have also provided information comparing survey respondent demographics to New Mexico Tumor Registry data on overall cancer incidence rates.

Respondent Relationship to the Cancer Patient/Survivor

Over 2/3 of the individuals who completed and returned the New Mexico Cancer Services Survey were cancer patients/survivors. Respondents also included spouses/significant others, children, parents, and other family members and loved ones. Figure 1 provides an overview of the respondent group.

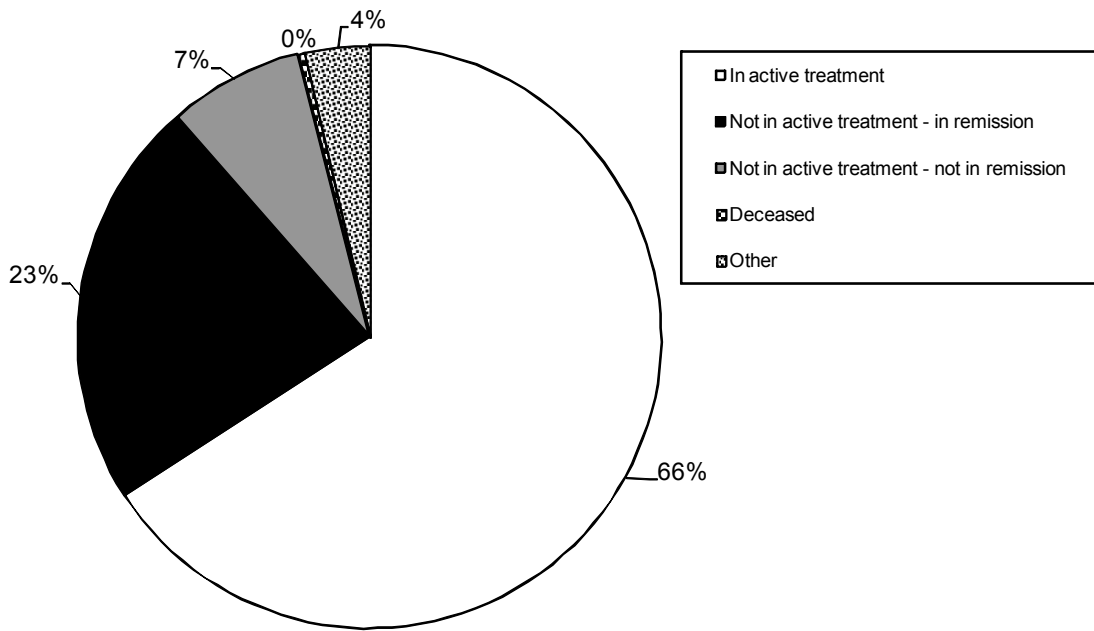
Figure 1: Relationship of Respondent to Cancer Patient/Survivor



Breakdown by Treatment Status

Most of the questionnaires were completed for individuals who were in active treatment. Figure 2 provides an overview of the current status of the cancer patients/survivors participating in the survey.

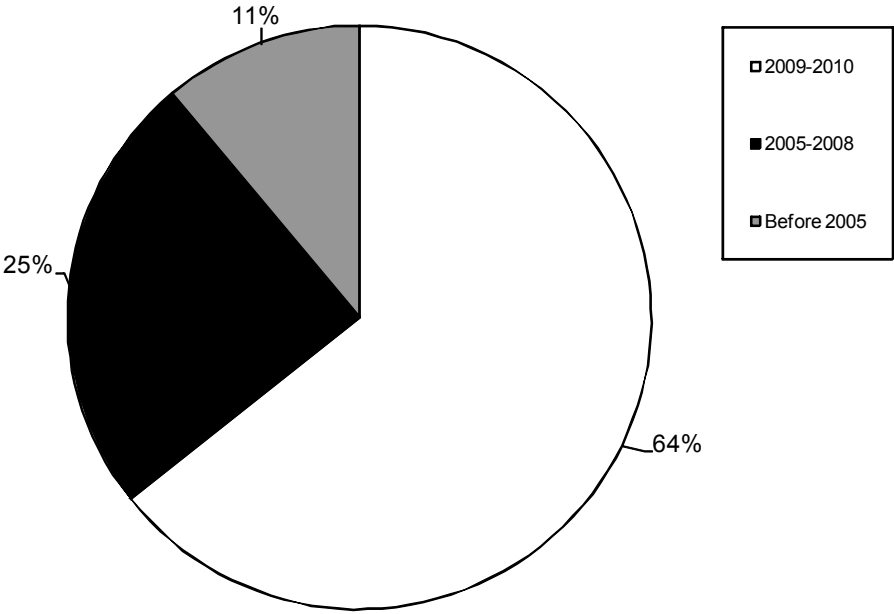
Figure 2: Current Status of the Cancer Patient/Survivor



Breakdown by Diagnosis Date

The majority of responses reflected the experiences of those whose most recent diagnosis was in 2009 or 2010. Figure 3 provides a breakdown of respondents by the date of the patient's most recent diagnosis

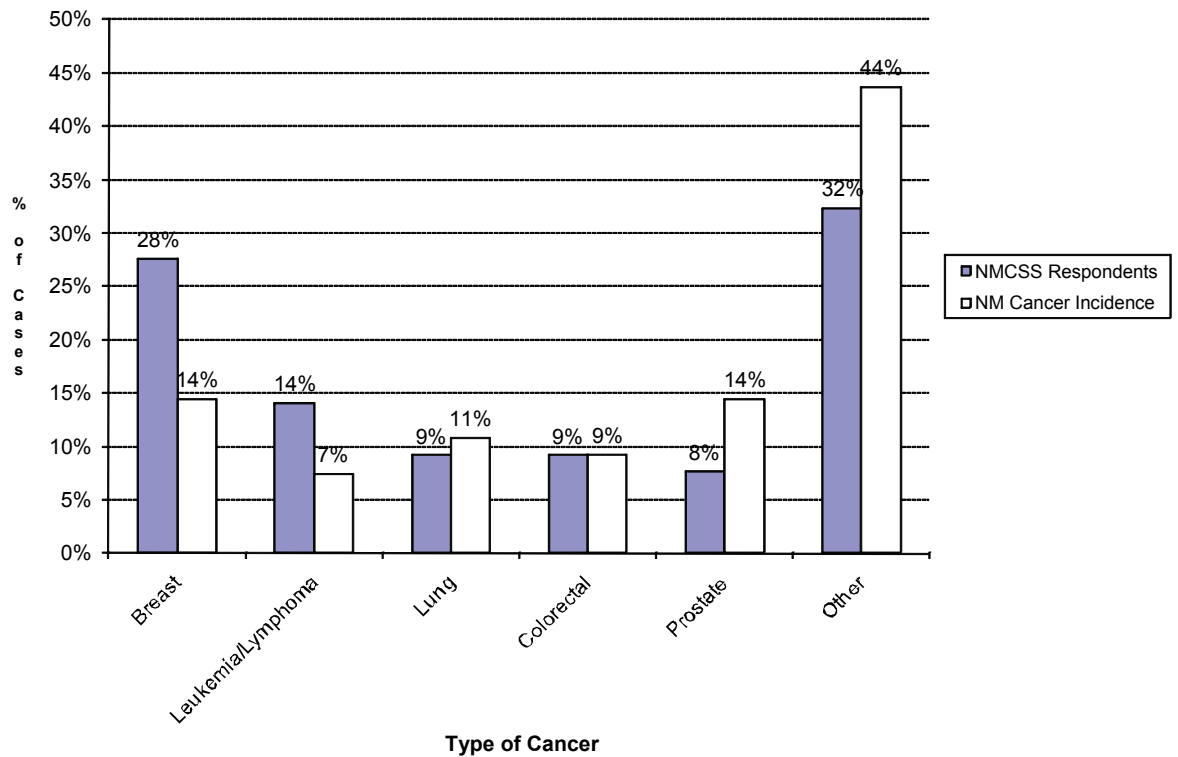
Figure 3: Year of Most Recent Diagnosis



Breakdown by Type of Cancer

Breast cancer and leukemia/lymphoma patients/survivors were represented in this study at a substantially higher rate than they appear in the overall population of New Mexicans coping with cancer. Patients/survivors with lung cancer and colorectal cancer were represented at rates similar to overall New Mexican incidence rates for these tumor types. Prostate cancer patients/survivors were represented at a lower rate than they appear in the overall New Mexican population. Over thirty additional types of tumors were listed by respondents. Figure 4 provides information on the types of cancer our survey respondents were facing, with comparisons to overall cancer incidence rates in New Mexico.¹

Figure 4: Comparison of Cancer Types to Overall NM Cancer Incidence

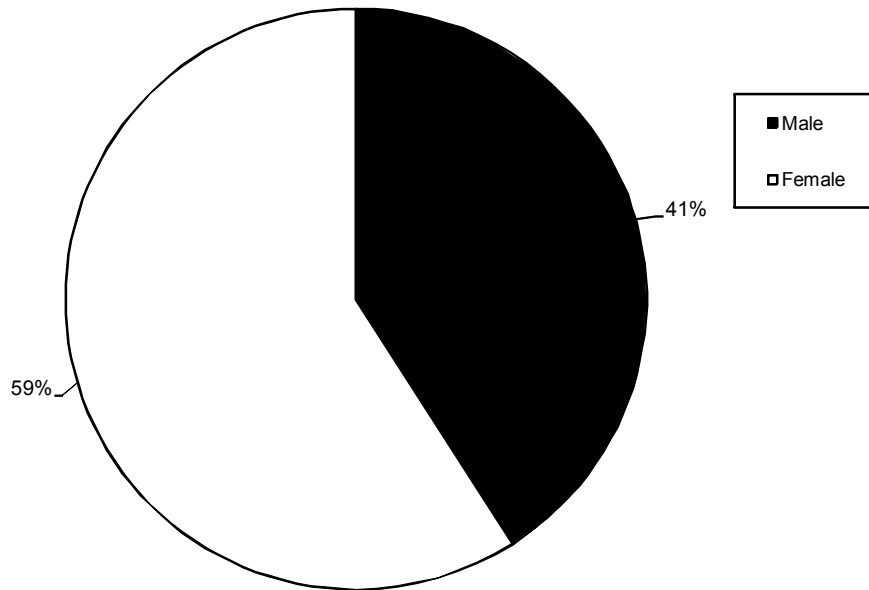


¹ All references to New Mexican cancer incidence rates in this report are based on statistics provided by the New Mexico Tumor Registry on cancer incidence among New Mexico residents in 2008, the most recent year for which data was available at the time of publication.

Breakdown by Patient's Gender

Not surprisingly, given the high incidence of breast cancer patients/survivors participating in the survey, the respondent group was skewed somewhat towards female patients/survivors. Figure 5 provides a breakdown of respondents by patient gender. By contrast, the overall New Mexican population diagnosed with cancer in 2008 was 49% female and 51% male.

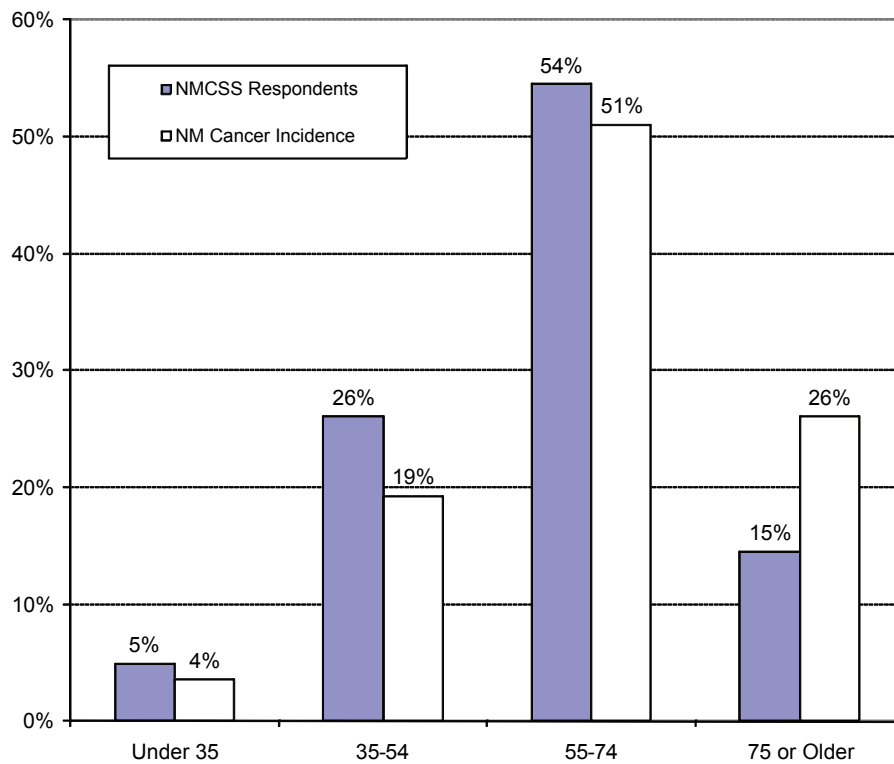
Figure 5: Patient's Gender



Breakdown by Patient's Age at Diagnosis

The New Mexico Cancer Services Survey focused solely on those who were diagnosed with cancer as adults. The age at diagnosis of the patient/survivor group we studied was similar to that of the overall New Mexican adult population diagnosed with cancer, although it was skewed a bit towards younger respondents. Figure 6 compares the age distribution of the patients/survivors in our survey to the broader population of New Mexicans coping with cancer.

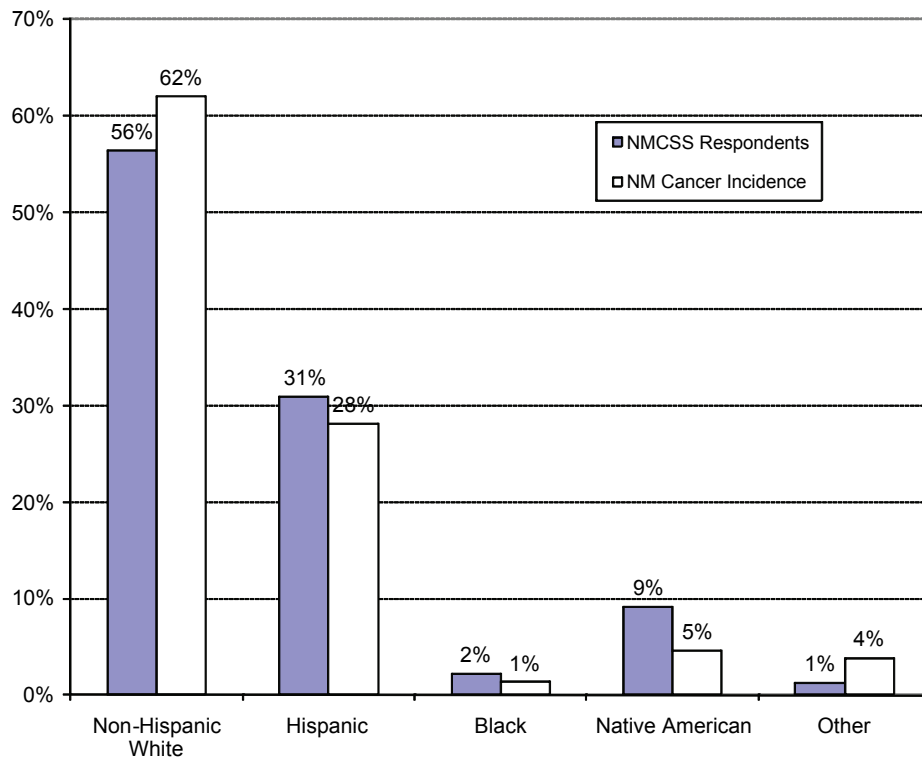
Figure 6: Comparison of Patient Age at Most Recent Diagnosis to Overall NM Cancer Incidence



Breakdown by Patient's Ethnic/Racial Group

Figure 7 compares the ethnic/racial mix of the patients/survivors in our study group to statewide statistics for cancer patients. The ethnic/racial mix of the patient/survivor group we studied was fairly similar to that of the overall New Mexican cancer patient population, although Native Americans were a bit over-represented.

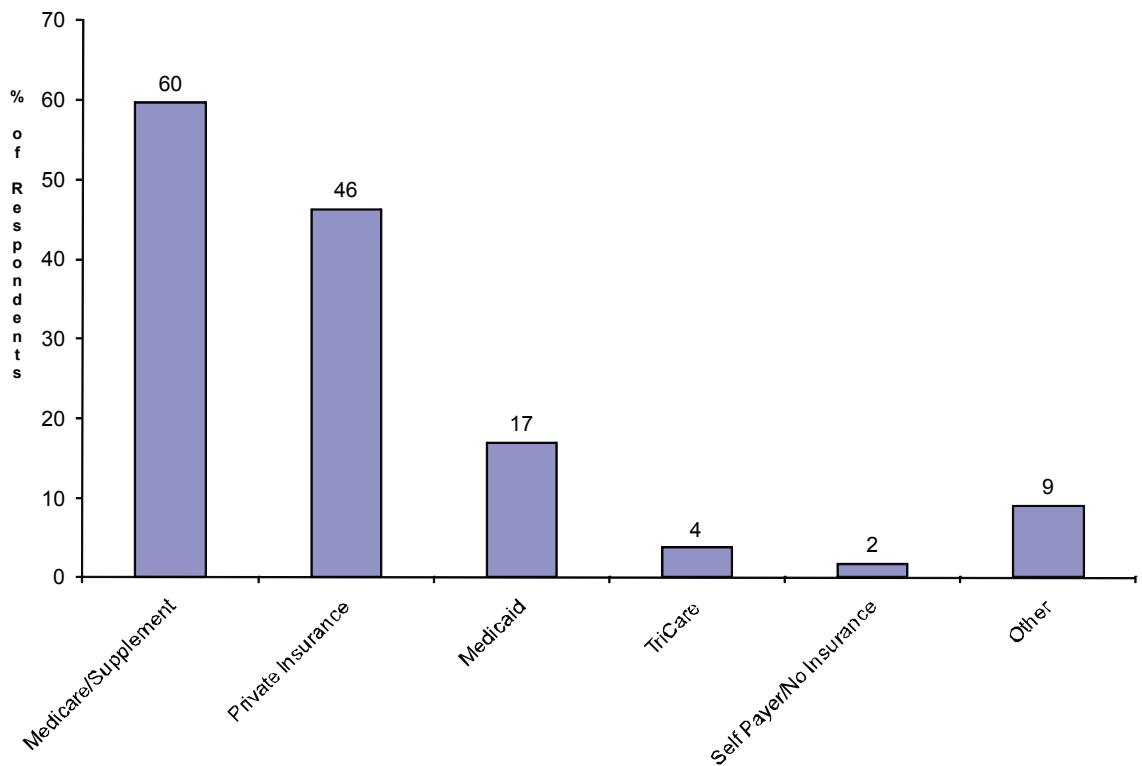
Figure 7: Comparison of Respondent Patient Ethnic/Racial Group to Overall NM Cancer Incidence



Breakdown by Patient's Insurance Coverage During Treatment

The majority of survey responses were for patients/survivors who had healthcare insurance through Medicare (with or without a Medicare supplement). Figure 8 provides information on the type of insurance coverage that patients/survivors had during treatment. The percentages sum to more than 100% because individuals were asked to indicate all forms of insurance coverage during treatment, and many respondents had more than one type of coverage.

Figure 8: Patient's Insurance Coverage During Treatment



Breakdown by Patient's Residence Location

Participants in this study came from all parts of New Mexico. Figure 9 provides a breakdown of respondents by the patient's county of residence. "Other" responses included ten patients/survivors from Arizona, two patients from Colorado, and one from Connecticut.

Figure 9: Patient's County of Residence

<u>Patient's County of Residence</u>	<u>Number</u>	<u>Percent</u>
Bernalillo County	160	37.6 %
Sandoval County	39	9.2 %
Dona Aña County	32	7.5 %
Santa Fe County	25	5.9 %
San Juan County	24	5.6 %
McKinley County	21	4.9 %
Valencia County	20	4.7 %
Taos County	13	3.1 %
Grant County	11	2.6 %
San Miguel County	11	2.6 %
Los Alamos County	10	2.4 %
Cibola County	9	2.1 %
Otero County	6	1.4 %
Luna County	4	0.9 %
Colfax County	4	0.9 %
Torrance County	4	0.9 %
Catron County	3	0.7 %
Chaves County	3	0.7 %
Rio Arriba County	3	0.7 %
Lincoln County	3	0.7 %
Socorro County	3	0.7 %
Eddy County	2	0.5 %
Sierra County	1	0.2 %
Hidalgo County	1	0.2 %
Other	13	3.1 %
Total	425	100.0 %

For analysis purposes, we evaluated geographic data in two ways: based on the five regions defined by the New Mexico Public Health Division, and based on a working definition of "urban" and "rural" regions developed by the Rural Workgroup of the New Mexico Cancer Council. Figures 10 and 11 compare the residence locations our survey population to overall cancer incidence rates in each of these areas.

Breakdown by NM Public Health Division Regions

The New Mexico Department of Health’s Public Health Division groups New Mexico’s counties into the following five regions:

- Region 1: San Juan, McKinley, Sandoval, Cibola, and Valencia
- Region 2: Rio Arriba, Taos, Colfax, Union, Los Alamos, Santa Fe, Mora, San Miguel, and Guadalupe
- Region 3: Bernalillo
- Region 4: Harding, Quay, DeBaca, Curry, Roosevelt, Chaves, and Lea
- Region 5: Torrance, Catron, Socorro, Lincoln, Grant, Sierra, Otero, Hidalgo, Luna, Dona Ana, and Eddy

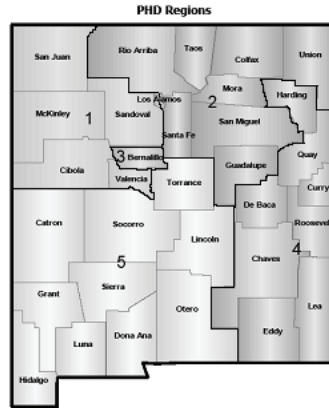
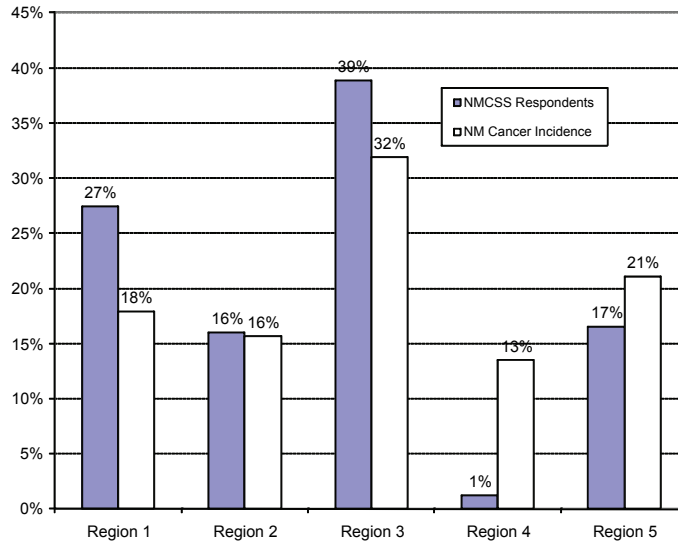


Figure 10 compares the residence locations of our study group by Public Health Division Region to statewide statistics for cancer patients. Because we were unable to conduct the survey in any clinics in the Eastern portion of New Mexico, Region 4 is significantly underrepresented in this study.

Figure 10: Patient’s Public Health Division Region



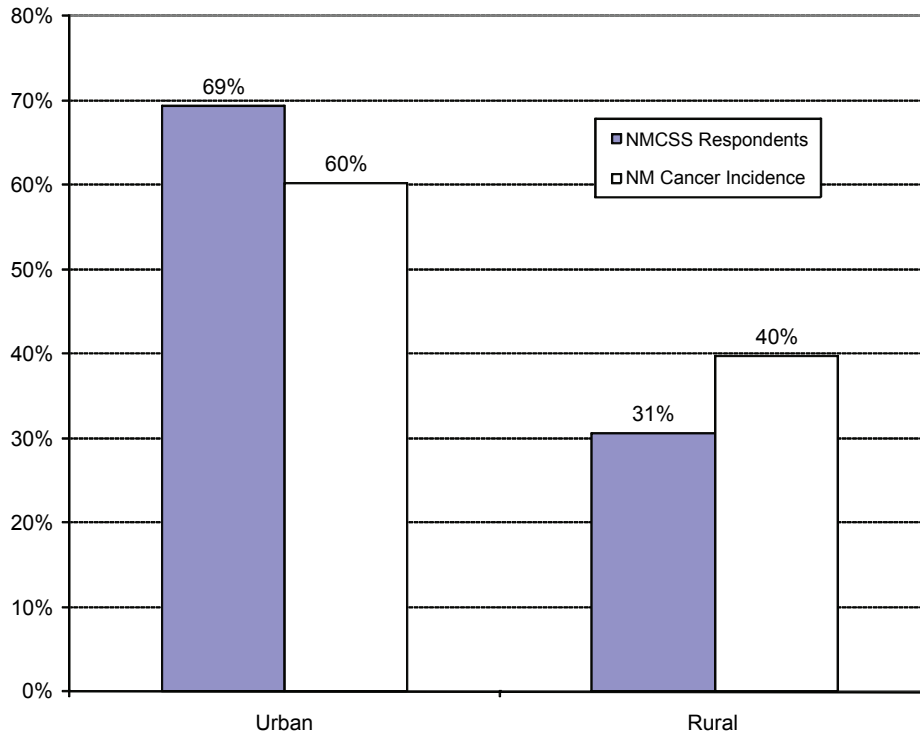
Breakdown by “Urban” vs. “Rural” Patients

The Rural Workgroup of the New Mexico Cancer Council has developed the following working definition for evaluating needs of urban vs. rural cancer patients/survivors:

- Urban: Residents of Bernalillo, Dona Aña, Los Alamos, Sandoval, Santa Fe, and Valencia Counties
- Rural: Residents of all other New Mexican counties

Figure 11 compares the number of “urban” and “rural” participants in our study to statewide statistics for cancer patients.

Figure 11: Urban vs. Rural Patients



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3. Importance of Different Cancer-Related Services

Respondents were asked to rate the importance of various cancer-related services to them, on a scale where 1=Low; 2=Moderate; 3=High; and 4=Very High. Figure 12 summarizes their responses.

Figure 12: Relative Importance of Cancer-Related Services

Service	Average Importance	# of Respondents
Traditional medical treatments (e.g., radiation, chemotherapy, surgery)	3.70	499
Early detection/screening	3.66	504
Information re: cancer-related services in NM	3.34	437
Education on managing the cancer process	3.34	457
Pain management/palliative care	3.30	432
Assistance with insurance issues	3.24	466
Emotional support programs for caregivers/family members	3.18	464
Emotional support programs for patients	3.18	482
Financial assistance for medical expenses	3.15	450
Hospice/end-of-life services	3.10	369
In-home care	2.97	408
Training in at-home management skills (e.g., administering medication)	2.94	408
Housing/lodging services (if treatment occurred away from home)	2.89	400
Transportation services to/from medical appointments	2.85	429
Financial assistance for non-medical expenses	2.85	434
Assistance with legal issues	2.82	436
Complementary/alternative therapies (e.g., herbs, acupuncture, meditation)	2.75	440

In general, services with a higher average importance rating were rated as having “high” or “very high” importance by more respondents than those with lower average importance ratings. For example, 94% of respondents rated traditional medical treatments as having “high” or “very high” importance, while only 60% of respondents rated complementary/alternative therapies as having “high” or “very high” importance.

T-tests were conducted to determine statistically significant differences in service importance based on various demographic criteria (tumor type, residence location, insurance type, gender, ethnic/racial group, etc.). Results from these additional tests are included in Section 8.



4. Satisfaction with New Mexico’s Cancer-Related Services

Respondents were asked to rate their satisfaction with ease of access and their satisfaction with service quality using the same list of cancer-related services that they rated for importance, on a scale where 1=Low; 2=Moderate; 3=High; and 4=Very High. Figures 13 and 14 summarize their responses.

Respondents were instructed that they should only answer the questions about ease of access for services that they needed, and should only answer the questions about service quality for services that they actually used. So, in most cases, substantially fewer people responded to these questions than responded to the question about the relative importance of different cancer-related services.

Figure 13: Respondent Satisfaction with Ease of Access to Needed Services

Service	Average Satisfaction	# of Respondents
Traditional medical treatments (e.g., radiation, chemotherapy, surgery)	3.65	417
Early detection/screening	3.35	400
Pain management/palliative care	3.30	243
Education on managing the cancer process	3.19	295
Hospice/end-of-life services	3.16	116
Assistance with insurance issues	3.15	277
Emotional support programs for patients	3.11	292
In-home care	3.09	159
Training in at-home management skills (e.g., administering medication)	3.08	163
Housing/lodging services (if treatment occurred away from home)	3.07	148
Information re: cancer-related services in NM	3.03	279
Financial assistance for medical expenses	2.99	230
Emotional support programs for caregivers/family members	2.96	266
Complementary/alternative therapies (e.g., herbs, acupuncture, meditation)	2.79	243
Transportation services to/from medical appointments	2.77	176
Assistance with legal issues	2.71	197
Financial assistance for non-medical expenses	2.69	192

In general, a larger percentage of respondents indicated a “high” or “very high” level of satisfaction with ease of access for higher rated services than for lower rated ones. For example, 93% of respondents indicated “high” or “very high” satisfaction with ease of access to traditional medical treatments, while only 56% indicated “high” or “very high” satisfaction with ease of access to financial assistance for non-medical expenses.

Figure 14: Respondent Satisfaction with the Quality of Services they Received/Used

Service	Average Satisfaction	# of Respondents
Traditional medical treatments (e.g., radiation, chemotherapy, surgery)	3.70	404
Early detection/screening	3.41	352
Pain management/palliative care	3.29	218
Education on managing the cancer process	3.21	268
Assistance with insurance issues	3.20	246
Emotional support programs for patients	3.19	233
Housing/lodging services (if treatment occurred away from home)	3.14	118
Hospice/end-of-life services	3.14	80
Training in at-home management skills (e.g., administering medication)	3.14	140
Emotional support programs for caregivers/family members	3.10	203
Information re: cancer-related services in NM	3.10	245
Financial assistance for medical expenses	3.08	192
In-home care	3.07	138
Transportation services to/from medical appointments	2.94	134
Complementary/alternative therapies (e.g., herbs, acupuncture, meditation)	2.94	178
Financial assistance for non-medical expenses	2.76	156
Assistance with legal issues	2.70	153

In general, a larger percentage of respondents indicated a “high” or “very high” level of satisfaction with service quality for higher rated services than for lower rated ones. For example, 93% of respondents indicated “high” or “very high” satisfaction with service quality for traditional medical treatments, while only 58% indicated “high” or “very high” satisfaction with service quality for assistance with legal issues.

Interestingly, the two services that were most important to respondents – traditional medical treatments and early detection/screening services – were also the two services where respondents were most satisfied with both ease of access and service quality.

T-tests were conducted to determine statistically significant differences in satisfaction with ease of access and service quality based on various demographic criteria (tumor type, residence region, insurance type, gender, ethnic/racial group, etc.). Results from these additional tests are included in Section 8.

5. Perceived Gaps in New Mexico’s Cancer-Related Services

Calculation of “Gap Ratings”

To understand perceived gaps in New Mexico’s cancer-related services we compared each respondent’s ratings of the importance of each cancer-related service with his or her satisfaction with ease of access and quality for that service. Specifically, the “gap ratings” for each service were calculated as:

$$\text{Access Gap Rating} = \text{Ease of Access Satisfaction Rating} - \text{Importance Rating}$$

$$\text{Quality Gap Rating} = \text{Quality Satisfaction Rating} - \text{Importance Rating}$$

An individual’s “access gap rating” for a service was only computed if the respondent rated both the importance of the service and his or her satisfaction with access to that service. Similarly, an individual’s “quality gap rating” for a service was only computed if the respondent rated both the importance of the service and his or her satisfaction with the quality of that service.

Negative “gap ratings” indicate that the average satisfaction rating for the service was lower than the average importance rating for the service. Larger gaps indicate greater discrepancies between the importance of a particular service offering to respondents and their satisfaction with that service offering.

Gaps in Ease of Access and Service Quality

Figures 15 and 16 summarize the “access gap ratings” and “quality gap ratings” computed for this study. Respondents’ satisfaction ratings were lower than their importance ratings for every service, resulting in negative “access gap scores” and “quality gap scores” for every service. **Services with the largest gaps (i.e., those nearer the top of each figure) may indicate areas with the greatest opportunity for improvement.**

Figure 15: Difference Between Importance of Cancer-Related Services and Satisfaction with Access to Needed Services

Service	Average Access Gap	# of Respondents
Financial assistance for non-medical expenses	-0.50	191
Transportation services to/from medical appointments	-0.44	175
Financial assistance for medical expenses	-0.44	228
Assistance with legal issues	-0.44	193
Emotional support programs for caregivers/family members	-0.41	265
Information re: cancer-related services in NM	-0.41	274
Early detection/screening	-0.35	396
Assistance with insurance issues	-0.32	274
Emotional support programs for patients	-0.31	289
Complementary/alternative therapies (e.g., herbs, acupuncture, meditation)	-0.27	239
Education on managing the cancer process	-0.27	292
Housing/lodging services (if treatment occurred away from home)	-0.24	147
In-home care	-0.23	155
Pain management/palliative care	-0.23	238
Training in at-home management skills (e.g., administering medication)	-0.19	158
Traditional medical treatments (e.g., radiation, chemotherapy, surgery)	-0.09	413
Hospice/end-of-life services	-0.07	107

Figure 16: Difference Between Importance of Cancer-Related Services and Satisfaction with Quality of Services Received/Used

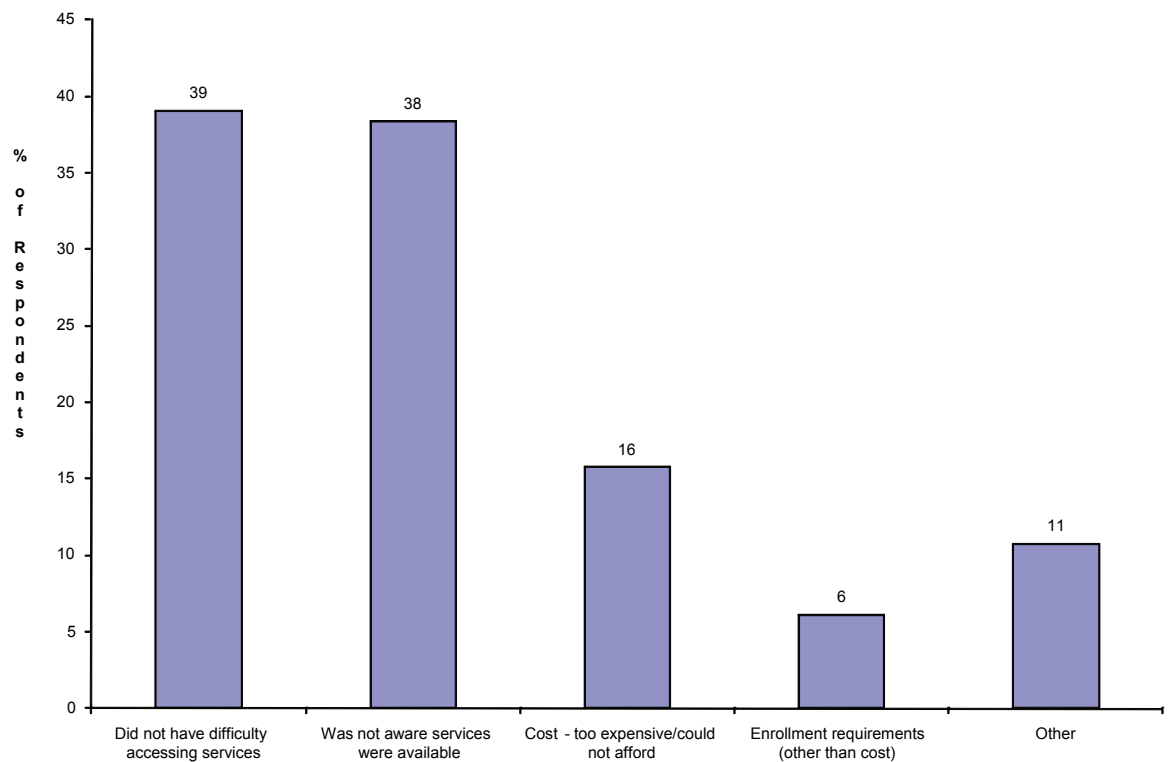
Service	Average Quality Gap	# of Respondents
Assistance with legal issues	-0.45	150
Financial assistance for medical expenses	-0.43	190
Financial assistance for non-medical expenses	-0.41	153
Transportation services to/from medical appointments	-0.39	131
Information re: cancer-related services in NM	-0.38	240
Education on managing the cancer process	-0.32	264
Assistance with insurance issues	-0.31	242
Emotional support programs for caregivers/family members	-0.30	199
Early detection/screening	-0.29	346
Emotional support programs for patients	-0.27	228
In-home care	-0.25	134
Pain management/palliative care	-0.25	212
Housing/lodging services (if treatment occurred away from home)	-0.21	117
Training in at-home management skills (e.g., administering medication)	-0.19	134
Complementary/alternative therapies (e.g., herbs, acupuncture, meditation)	-0.08	176
Traditional medical treatments (e.g., radiation, chemotherapy, surgery)	-0.06	399
Hospice/end-of-life services	-0.05	77

Since respondents were instructed to only answer the “ease of access” and “service quality” questions for services they needed and/or used, there is substantial variability in the number of responses to each question. In particular, traditional medical treatments and early detection/screening services, which are relevant to virtually every cancer patient/survivor, received far more responses than other services.

It is interesting to note that the four services at the top of Figures 15 and 16 (financial assistance for medical and non-medical expenses, assistance with legal issues, and transportation services to/from medical appointments) were rated relatively low in average overall importance (Figure 12). This seems to indicate that while these services are only important to a subset of those coping with cancer, significant gaps exist for those who need them.

Further insights into respondents' perceptions of gaps in cancer-related services can be gained through a review of responses to several other questions on the survey. In Question 8, respondents were asked to identify factors that limited their access to services. Figure 17 summarizes their responses. The total sums to more than 100% because respondents were able to indicate more than one factor limiting their access to services.

Figure 17: Factors Limiting Access to Needed Cancer-Related Services



Over 60% of respondents to this question indicated they had difficulty accessing services that they needed. The primary reason was that respondents were not aware that services were available to help them. While in some instances this gap may be due to the actual absence of necessary services, it is likely that this number could be significantly reduced through improved efforts to educate cancer patients/survivors and their loved ones about available services.

Respondents were provided with space to provide additional comments regarding factors limiting their access to services. These included lack of timely diagnosis/treatment, transportation/travel issues, and a variety of other factors. A full listing of comments regarding limitations to service access is included in Appendix C.

Question 11 asked respondents what cancer-related services they needed that did not exist to support them and Question 12 asked respondents what cancer-related services they would want to see improved, and how they would improve these services. In response to Question 12, there were **far more comments about the need for improved information and education than about any other subject area**. A full listing of these comments is included in Appendices D and E.

T-tests were conducted to determine statistically significant differences in gap ratings based on various demographic criteria (tumor type, residence region, insurance type, gender, ethnic/racial group, etc.). Results from these additional tests are included in Section 8.



6. Sources of Information for Patients/Survivors and Their Loved Ones

Respondents were asked to rate how helpful various groups were in providing information on what cancer-related services were available, with a rating scale of 1=Not Helpful; 2=Somewhat Helpful; 3=Helpful; 4=Very Helpful. Figure 18 summarizes their responses.

Figure 18: Helpfulness in Providing Information on Availability of Cancer-Related Services

Information Source	Average Helpfulness	# Respondents
Nurses	3.59	428
Physicians	3.52	438
Independent reading/internet searches	3.35	277
Social workers	3.16	225
Cancer support group(s)	3.12	193
Cancer agencies/organizations	3.06	207
Other	3.72	32

“Other” information sources included friends and family, other patients, cancer navigators, radiation techs, and a variety of other sources.

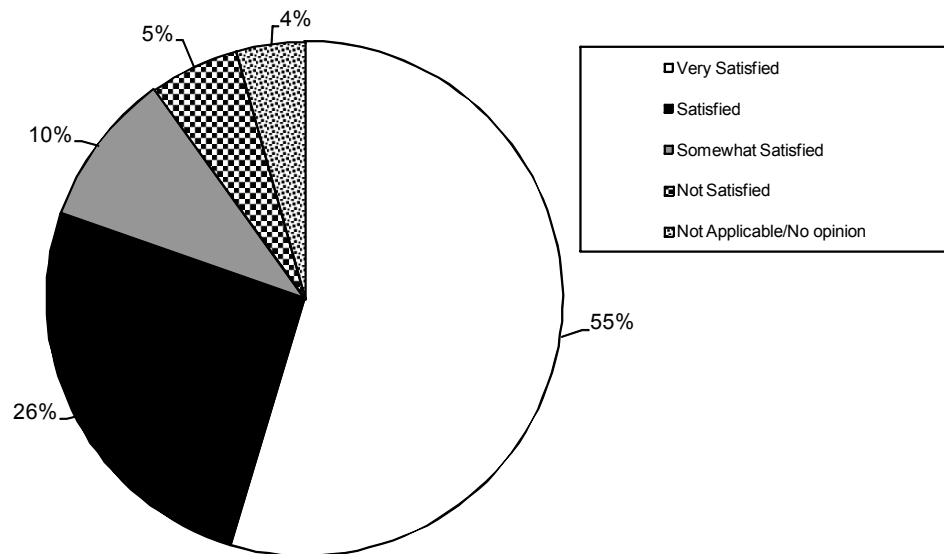
It is interesting to note that fewer than half of the respondents rated the helpfulness of social workers, cancer support groups, or cancer agencies/organizations. This may indicate that many respondents did not have contact with these resources.

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7. Satisfaction with Coordination/Communication Between Providers

Respondents were asked to rate how satisfied they were with the coordination/communication between different medical providers (oncologists, surgeons, primary care providers, etc.). Over 80% of respondents indicated that they were satisfied or very satisfied with these communications. Figure 19 summarizes their responses.

Figure 19: Satisfaction with Coordination/Communication Between Medical Providers



Respondents' open-ended comments regarding coordination/communication between medical providers are included in Appendix F. Areas identified for improvement include coordination between oncologists and primary care providers, and coordination between oncologists and surgeons.

8. Differences Among Demographic Groups

Responses to the New Mexico Cancer Services Survey were analyzed to identify differences in responses by different demographic groups. These findings may be helpful as cancer services providers seek to customize their offerings to address disparities and to best meet the needs of the different segments of the patient population that they serve.

This section summarizes differences among respondents by:

- Respondent type (patient/survivor, spouse/significant other, etc.)
- Treatment status (in active treatment, in remission, etc.)
- Year of most recent diagnosis
- Tumor type
- Patient’s gender
- Patient’s age at most recent diagnosis
- Patient’s ethnic/racial group
- Patient’s insurance type during treatment
- Patient’s region of residence during treatment (e.g., NM Public Health Division region, rural vs. urban)

In each case we list the top three areas of importance, the three largest “access gap rating” areas, and the three largest “quality gap rating” areas for each demographic group. In addition, T-tests were conducted to determine statistically significant differences in ratings between demographic groups.

Comparisons by Respondent Type

This section compares responses by those who identified themselves as patients/survivors to those who identified themselves as a spouse/significant other, parent, or child of the patient.

Figure 20: Most Important Services by Respondent Type

Respondent Type	Most Important Services	Average Importance	# Respondents
Patient/ Survivor	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.70	330
	• Early detection/screening	3.63	331
	• Information re: cancer-related services in NM	3.28	287
	• Education on managing the cancer process	3.28	298
Spouse/ Sign. Other/ Parent/Child	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.80	125
	• Early detection/screening	3.76	130
	• Information re: cancer-related services in NM	3.51	110

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients/survivors** rated emotional support programs for patients, emotional support programs for caregivers/family members, assistance with legal issues, assistance with insurance issues, in-home care, training in at-home management skills, and hospice/end-of-life services as significantly less important than other respondents did

Figure 21: Largest Access “Gaps” by Respondent Type

Respondent Type	Services with the Largest Access “Gap”	Average Gap	# Respondents
Patient/ Survivor	• Financial assistance for medical expenses	-0.50	145
	• Financial assistance for non-medical expenses	-0.47	123
	• Assistance with legal issues	-0.41	123
Spouse/ Sign. Other/ Parent/Child	• Financial assistance for non-medical expenses	-0.71	24
	• Assistance with legal issues	-0.66	29
Parent/Child	• Information re: cancer-related services in NM	-0.62	50

No significant differences in access gaps were identified by respondent type.

Figure 22: Largest Quality “Gaps” by Respondent Type

Respondent Type	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Patient/ Survivor	<ul style="list-style-type: none"> • Assistance with legal issues 	-0.48	103
	<ul style="list-style-type: none"> • Financial assistance for medical expenses • Financial assistance for non-medical expenses 	-0.47	122
		-0.42	98
Spouse/ Sign. Other/ Parent/Child	<ul style="list-style-type: none"> • Assistance with legal issues 	-0.55	31
	<ul style="list-style-type: none"> • Transportation services to/from medical appts. 	-0.53	30
	<ul style="list-style-type: none"> • Information re: cancer-related services in NM 	-0.52	60

The following differences in quality gap ratings were determined to be statistically significant at the level of p=.05:

- **Patients/survivors** reported a significantly larger quality gap for hospice/end of life services than other respondents

Comparisons by Treatment Status

This section compares responses from those in active treatment (chemo, radiation, etc.) with other respondents.

Figure 23: Most Important Services by Treatment Status

Treatment Status	Most Important Services	Average Importance	# Respondents
In Active Treatment	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.74	310
	• Early detection/screening	3.62	311
	• Education on managing the cancer process	3.36	286
Not In Active Treatment/ Deceased/ Other	• Early detection/screening	3.71	160
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.61	158
	• Information re: cancer-related services in NM	3.30	140
	• Education on managing the cancer process	3.30	144

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- Respondents **in active treatment** rated financial assistance for medical expenses, financial assistance for non-medical expenses, and in-home care as significantly more important than other respondents did

Figure 24: Largest Access “Gaps” by Treatment Status

Treatment Status	Services with the Largest Access “Gap”	Average Gap	# Respondents
In Active Treatment	• Financial assistance for non-medical expenses	-0.56	118
	• Transportation services to/from medical appts.	-0.52	108
	• Financial assistance for medical expenses	-0.51	147
Not In Active Treatment/ Deceased/ Other	• Emotional support programs for caregivers/family	-0.41	86
	• Training in at-home management skills	-0.40	50
	• Financial assistance for medical expenses	-0.35	69

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- Respondents **in active treatment** reported a significantly larger access gap for complementary/alternative therapies than other respondents

Figure 25: Largest Quality “Gaps” by Treatment Status

Treatment Status	Services with the Largest Quality “Gap”	Average Gap	# Respondents
In Active Treatment	• Assistance with legal issues	-0.52	93
	• Financial assistance for medical expenses	-0.46	117
	• Transportation services to/from medical appts.	-0.43	80
Not in Active Treatment/Deceased/Other	• Financial assistance for non-medical expenses	-0.43	51
	• Housing/lodging services (if treatment occurred away from home)	-0.41	37
	• Financial assistance for medical expenses	-0.40	60

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- Respondents **in active treatment** reported a significantly larger quality gap for traditional medical treatments (e.g., radiation, chemotherapy, surgery) than other respondents did

Comparisons by Year of Most Recent Diagnosis

This section compares responses for patients diagnosed in 2009-2010 to those diagnosed from 2005-2008 and those diagnosed before 2005. Respondents with more than one cancer diagnosis were asked to provide the year of their most recent diagnosis.

Figure 26: Most Important Services by Date of Diagnosis

Diagnosis Date	Most Important Services	Average Importance	# Respondents
2009-2010	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.71	279
	• Early detection/screening	3.67	279
	• Education on managing the cancer process	3.35	257
2005-2008	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.78	90
	• Early detection/screening	3.69	90
	• Information re: cancer-related services in NM	3.59	82
Before 2005	• Early detection/screening	3.63	49
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.63	48
	• Emotional support programs for caregivers/family	3.22	45

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- Those responding regarding **diagnoses in 2009-10** rated housing/lodging services and hospice/end of life services as significantly less important than other respondents did
- Those responding regarding **diagnoses in 2005-2008** rated pain management/palliative care, hospice/end-of-life services, and information regarding cancer-related services in New Mexico as significantly more important than other respondents did
- Those responding regarding **diagnoses before 2005** rated education on managing the cancer process as significantly less important than other respondents did

Figure 27: Largest Access “Gaps” by Diagnosis Date

Diagnosis Date	Services with the Largest Access “Gap”	Average Gap	# Respondents
2009-2010	• Transportation services to/from medical appts.	-0.51	107
	• Emotional support programs for caregivers/family	-0.45	154
	• Financial assistance for non-medical expenses	-0.41	114
	• Information re: cancer-related services in NM	-0.41	158
2005-2008	• Financial assistance for medical expenses	-0.79	42
	• Financial assistance for non-medical expenses	-0.73	37
	• Early detection/screening	-0.64	70
	• Information re: cancer-related services in NM	-0.64	55
Before 2005	• Assistance with legal issues	-0.38	16
	• Emotional support programs for caregivers/family	-0.25	24
	• Early detection/screening	-0.23	35

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- Those responding regarding **diagnoses in 2005-2008** reported a significantly larger access gap for financial assistance for medical expenses than other respondents did
- Those responding regarding **diagnoses before 2005** reported a significantly smaller access gap for complementary/alternative therapies than other respondents did

Figure 28: Largest Quality “Gaps” by Diagnosis Date

Diagnosis Date	Services with the Largest Quality “Gap”	Average Gap	# Respondents
2009-2010	• In-home care	-0.43	81
	• Assistance with legal issues	-0.42	88
	• Transportation services to/from medical appts.	-0.41	80
2005-2008	• Financial assistance for medical expenses	-0.64	36
	• Education on managing the cancer process	-0.62	50
	• Transportation services to/from medical appts.	-0.57	21
Before 2005	• Financial assistance for non-medical expenses	-0.54	13
	• Assistance with legal issues	-0.54	13
	• Assistance with insurance issues	-0.50	20

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- Those responding regarding **diagnoses in 2009-2010** reported a significantly larger quality gap for in-home care than other respondents did
- Those responding regarding **diagnoses in 2005-2008** reported a significantly smaller quality gap for in-home care and hospice/end of life services than other respondents did

Comparisons by Tumor Type

This section compares responses for patients with the different tumor types most prevalent among respondents,

Figure 29: Most Important Services by Tumor Type

Tumor Type	Most Important Services	Average Importance	# Respondents
Breast	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.71	123
	• Early detection/screening	3.70	125
	• Education on managing the cancer process	3.42	116
Colorectal	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.68	38
	• Early detection/screening	3.58	43
	• Information re: cancer-related services in NM	3.37	35
Leukemia/ Lymphoma	• Early detection/screening	3.81	62
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.76	62
	• Information re: cancer-related services in NM	3.28	54
Lung	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.76	38
	• Early detection/screening	3.74	39
	• Information re: cancer-related services in NM	3.43	35
Prostate	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.74	35
	• Early detection/screening	3.63	35
	• Pain management/palliative care	3.56	32

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Breast cancer** respondents rated assistance with insurance issues and financial assistance for non-medical expenses as significantly more important than other respondents did

Figure 30: Largest Access “Gaps” by Tumor Type

Tumor Type	Services with the Largest Access “Gap”	Average Gap	# Respondents
Breast	• Pain management/palliative care	-0.44	61
	• Transportation services to/from medical appts.	-0.43	47
	• Financial assistance for medical expenses	-0.40	63
Colorectal	• Financial assistance for non-medical expenses	-0.58	19
	• Assistance with legal issues	-0.44	18
	• Information re: cancer-related services in NM	-0.43	21
Leukemia/ Lymphoma	• Financial assistance for medical expenses	-0.56	27
	• Assistance with legal issues	-0.55	22
	• Financial assistance for non-medical expenses	-0.55	19
Lung	• Transportation services to/from medical appts.	-1.09	11
	• Housing/lodging services (if treatment occurred away from home)	-0.80	10
	• Financial assistance for non-medical expenses	-0.75	12
Prostate	• Assistance with legal issues	-1.00	10
	• Transportation services to/from medical appts.	-0.91	11
	• Emotional support programs for patients	-0.67	21

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Breast cancer** respondents reported a significantly larger access gap for pain management/palliative care services than other respondents did
- **Lung cancer** respondents reported a significantly larger access gap for housing/lodging services and a significantly smaller access gap for education on managing the cancer process than other respondents did

Figure 31: Largest Quality “Gaps” by Tumor Type

Tumor Type	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Breast	• Pain management/palliative care	-0.39	54
	• Early detection/screening	-0.34	93
	• Financial assistance for non-medical expenses	-0.33	45
Colorectal	• Assistance with legal issues	-0.50	14
	• Housing/lodging services (if treatment occurred away from home)	-0.30	10
	• In-home care	-0.27	15
Leukemia/ Lymphoma	• Financial assistance for non-medical expenses	-0.78	18
	• Assistance with legal issues	-0.63	19
	• Education on managing the cancer process	-0.61	31
Lung	• Transportation services to/from medical appts.	-1.50	4
	• Financial assistance for non-medical expenses	-1.00	7
	• Assistance with legal issues	-0.88	8
Prostate	• Transportation services to/from medical appts.	-1.00	9
	• Assistance with legal issues	-0.78	9
	• Emotional support programs for caregivers/family	-0.50	12

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Breast cancer** respondents reported a significantly smaller quality gap for assistance with legal issues and information regarding cancer-related services in New Mexico than other respondents did
- **Lung cancer** respondents and **prostate cancer** respondents reported a significantly larger quality gap for transportation services to/from medical appointments than other respondents did

Comparisons by Patient's Gender

This section compares responses based on the gender of the patient/survivor.

Figure 32: Most Important Services by Patient Gender

Patient Gender	Most Important Services	Average Importance	# Respondents
Male	• Early detection/screening)	3.75	182
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.71	182
	• Information re: cancer-related services in NM	3.34	161
Female	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.72	266
	• Early detection/screening	3.66	270
	• Education on managing the cancer process	3.39	244

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Female** patients/survivors rated emotional support programs for patients as significantly more important than **male** respondents did

Figure 33: Largest Access “Gaps” by Patient Gender

Patient Gender	Services with the Largest Access “Gap”	Average Gap	# Respondents
Male	• Financial assistance for non-medical expenses	-0.63	65
	• Assistance with legal issues	-0.55	62
	• Financial assistance for medical expenses	-0.51	81
Female	• Transportation services to/from medical appts.	-0.49	97
	• Financial assistance for non-medical expenses	-0.47	108
	• Financial assistance for medical expenses	-0.42	126

No significant differences in access gaps were identified by gender.

Figure 34: Largest Quality “Gaps” by Patient Gender

Respondent Type	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Male	• Transportation services to/from medical appts.	-0.60	47
	• Financial assistance for non-medical expenses	-0.57	54
	• Assistance with legal issues	-0.57	51
Female	• Financial assistance for medical expenses	-0.40	107
	• Financial assistance for non-medical expenses	-0.39	83
	• Assistance with legal issues	-0.39	84

No significant differences in quality gaps were identified by gender.

Comparisons by Patient's Age at Diagnosis

This section compares responses based on the patient's/survivor's age at their most recent diagnosis.

Figure 35: Most Important Services by Age at Diagnosis

Age at Diagnosis	Most Important Services	Average Importance	# Respondents
Under 35	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.73	22
	• Early detection/screening	3.71	21
	• Information re: cancer-related services in NM	3.47	19
35-54	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.68	115
	• Early detection/screening	3.57	115
	• Education on managing the cancer process	3.41	110
55-74	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.73	245
	• Early detection/screening	3.72	246
	• Information re: cancer-related services in NM	3.39	215
75 and Older	• Early detection/screening	3.80	64
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.68	62
	• Education on managing the cancer process	3.32	57

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed between ages 55-74** rated hospice/end-of-life services as significantly more important than other respondents did
- **Patients diagnosed at ages 75 and over** rated complementary/alternative therapies, financial assistance for medical expenses, and housing/lodging services as significantly less important than other respondents did

Figure 36: Largest Access “Gaps” by Age at Diagnosis

Age at Diagnosis	Services with the Largest Access “Gap”	Average Gap	# Respondents
Under 35	• Early detection/screening	-1.00	16
	• Financial assistance for non-medical expenses	-0.83	12
	• Information re: cancer-related services in NM	-0.73	11
35-54	• Assistance with legal issues	-0.63	19
	• Emotional support program for caregivers/family	-0.54	18
	• Information re: cancer-related services in NM	-0.52	21
55-74	• Financial assistance for medical expenses	-0.59	103
	• Financial assistance for non-medical expenses	-0.56	84
	• Assistance with legal issues	-0.49	96
75 and Older	• Transportation services to/from medical appts.	-1.05	21
	• Financial assistance for non-medical expenses	-0.65	17
	• Training in at-home management skills (e.g., administering medication)	-0.41	17

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed before age 35** reported a significantly larger access gap for early detection/screening and a significantly smaller access gap for assistance with legal issues than other respondents did
- **Patient diagnosed at age 75 and older** respondents reported a significantly smaller access gap for emotional support programs for patients, hospice/end-of-life services, education on managing the cancer process, and information regarding cancer-related services in New Mexico than other respondents did, and a significantly larger access gap for transportation services to/from medical appointments than other respondents did

Figure 37: Largest Quality “Gaps” by Age at Diagnosis

Age at Diagnosis	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Under 35	• Financial assistance for non-medical expenses	-1.00	11
	• Financial assistance for medical expenses	-1.00	14
	• Housing/lodging services (if treatment occurred away from home)	-1.00	10
	• Education on managing the cancer process	-1.00	12
35-54	• Assistance with legal issues	-0.56	41
	• Emotional support programs for patients	-0.38	60
	• Information re: cancer-related services in NM	-0.35	63
55-74	• Financial assistance for non-medical expenses	-0.53	66
	• Transportation services to/from medical appts.	-0.47	64
	• Financial assistance for medical expenses	-0.45	84
75 and Older	• Assistance with legal issues	-0.88	8
	• Transportation services to/from medical appts.	-0.67	12
	• Financial assistance for non-medical expenses	-0.50	12
	• Training in at-home management skills (e.g., administering medication)	-0.50	16

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed before age 35** reported a significantly larger quality gap for financial assistance for medical expenses, housing/lodging services, pain management/palliative care, and education on managing the cancer process than other respondents did
- **Patients diagnosed between aged 35-54** reported a significantly smaller quality gap for housing/lodging services than other respondents did
- **Patients diagnosed over age 75** reported a significantly smaller quality gap for hospice/end-of-life services and education on managing the cancer process than other respondents did

Comparisons by Patient's Ethnic/Racial Group

This section compares responses for Hispanic, Non-Hispanic White, and Native American patients/survivors.

Figure 38: Most Important Services by Ethnic/Racial Group

Ethnic/Racial Group	Most Important Services	Average Importance	# Respondents
Hispanic	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.65	135
	• Early detection/screening	3.57	136
	• Education on managing the cancer process	3.45	123
Non-Hispanic White	• Early detection/screening	3.75	249
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.74	244
	• Information re: cancer-related services in NM	3.42	221
Native American	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.54	41
	• Early detection/screening	3.50	40
	• Financial assistance for medical expenses	3.30	40

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Hispanic** respondents rated complementary/alternative therapies, assistance with legal issues, assistance with insurance issues, financial assistance with medical expenses, and housing/lodging services as significantly more important than other respondents did
- **Non-Hispanic White** respondents rated early detection/screening services as significantly more important than other respondents did and rated complementary/alternative therapies and financial assistance with medical expenses as significantly less important than other respondents did
- **Native American** respondents rated assistance with legal issues, assistance with insurance issues, housing/lodging services, pain management/palliative care, hospice/end-of-life service, education on managing the cancer process, and information regarding cancer-related services in New Mexico as significantly less important than other respondents did

Figure 39: Largest Access “Gaps” by Ethnic/Racial Group

Ethnic/Racial Group	Services with the Largest Access “Gap”	Average Gap	# Respondents
Hispanic	• Education on managing the cancer process	-0.39	85
	• Information re: cancer-related services in NM	-0.33	82
	• Assistance with legal issues	-0.30	67
Non-Hispanic White	• Financial assistance for non-medical expenses	-0.68	78
	• Financial assistance for medical expenses	-0.63	87
	• Transportation services to/from medical appts.	-0.55	64
Native American	• Transportation services to/from medical appts.	-0.36	25
	• Financial assistance for non-medical expenses	-0.32	25
	• Financial assistance for medical expenses	-0.26	31

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Hispanic** respondents reported a significantly smaller access gap for complementary/alternative therapies, emotional support programs for patients, financial assistance for medical expenses, financial assistance for non-medical expenses, and transportation services to/from medical appointments than other respondents did
- **Non-Hispanic White** respondents reported a significantly larger access gap for early detection/screening, traditional medical treatments, complementary/alternative therapies, emotional support programs for patients, emotional support programs for caregivers/family members, assistance with insurance issues, financial assistance for medical expenses, financial assistance for non-medical expenses, and information regarding cancer-related services in New Mexico than other respondents did
- **Native American** respondents reported a significantly smaller access gap for traditional medical treatments, pain management/palliative care, education on managing the cancer process, and information regarding cancer-related services in New Mexico than other respondents did

Figure 40: Largest Quality “Gaps” by Ethnic/Racial Group

Ethnic/Racial Group	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Hispanic	• Education on managing the cancer process	-0.41	81
	• In-home care	-0.32	88
	• Assistance with legal issues	-0.27	80
	• Financial assistance for medical expenses	-0.27	66
Non-Hispanic White	• Assistance with legal issues	-0.65	57
	• Financial assistance for non-medical expenses	-0.59	54
	• Financial assistance for medical expenses	-0.58	67
Native American	• Transportation services to/from medical appts.	-0.54	13
	• Financial assistance for non-medical expenses	-0.54	13
	• Financial assistance for medical expenses	-0.50	20

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Hispanic** respondents reported a significantly smaller quality gap for transportation services to/from medical appointments than other respondents did
- **Non-Hispanic White** respondents reported a significantly larger quality gap for emotional support programs for caregivers/family members, assistance with legal issues, assistance with insurance issues, financial assistance for medical expenses and information regarding cancer-related services in New Mexico than other respondents did
- **Native American** respondents reported a significantly smaller quality gap for traditional medical treatments, pain management/palliative care, and education on managing the cancer process than other respondents did

Comparisons by Patient's Insurance Type During Treatment

This section compares responses based on the type of insurance coverage the patient had during treatment – Medicaid; Medicare (including those with a Medicare Supplement); and Private Insurance (HMO/PPO/Indemnity).

Figure 41: Most Important Services by Insurance Type

Insurance Type	Most Important Services	Average Importance	# Respondents
Medicaid	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.82	72
	• Early detection/screening	3.71	70
	• Financial assistance for medical expenses	3.54	70
Medicare/Medicare Supplement	• Early detection/screening	3.69	216
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.69	212
	• Information re: cancer-related services in NM	3.34	186
Private Insurance	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.75	200
	• Early detection/screening	3.72	199
	• Education on managing the cancer process	3.39	185

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Medicaid** respondents rated complementary/alternative therapies, emotional support programs for patients, emotional support programs for caregivers/family members, financial assistance for medical expenses, financial assistance for non-medical expenses, transportation services to/from medical appointments, and housing/lodging services as significantly more important than other respondents did
- **Medicare/Medicare Supplement** respondents rated complementary/alternative therapies, assistance with insurance issues, and financial assistance for medical expenses as significantly less important than other respondents did, and rated in-home care as significantly more important than other respondents did
- **Private Insurance** respondents rated financial assistance for medical expenses as significantly less important than other respondents did

Figure 42: Largest Access “Gaps” by Insurance Type

Insurance Type	Services with the Largest Access “Gap”	Average Gap	# Respondents
Medicaid	• Early detection/screening	-0.52	85
	• Financial assistance for non-medical expenses	-0.33	82
	• Transportation services to/from medical appts.	-0.27	67
	• Emotional support programs for caregivers/family	-0.27	41
Medicare/Medicare Supplement	• Transportation services to/from medical appts.	-0.53	73
	• Financial assistance for non-medical expenses	-0.48	71
	• Financial assistance for medical expenses	-0.45	83
	• Assistance with legal issues	-0.45	69
Private Insurance	• Assistance with legal issues	-0.55	73
	• Financial assistance for non-medical expenses	-0.48	62
	• Information re: cancer-related services in NM	-0.46	112

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Medicaid** respondents reported a significantly smaller access gap for assistance with legal issues, assistance with insurance issues and financial assistance for medical expenses than other respondents did
- **Medicare/Medicare Supplement** respondents reported a significantly smaller access gap for education on managing the cancer process than other respondents did

Figure 43: Largest Quality “Gaps” by Insurance Type

Insurance Type	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Medicaid	• Transportation services to/from medical appts.	-0.29	35
	• Financial assistance for medical expenses	-0.28	46
	• Pain management/palliative care	-0.27	37
Medicare/Medicare Supplement	• Assistance with legal issues	-0.48	48
	• Financial assistance for non-medical expenses	-0.46	54
Private Insurance	• Transportation services to/from medical appts.	-0.38	50
	• Assistance with legal issues	-0.58	50
	• Financial assistance for medical expenses	-0.45	55
	• Education on managing the cancer process	-0.43	107

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Medicaid** respondents reported a significantly smaller quality gap for assistance with legal issues than other respondents did
- **Medicare/Medicare Supplement** respondents reported a significantly smaller quality gap for assistance with insurance issues and education on managing the cancer process than other respondents did

Comparisons by Patient's Region of Residence

Respondents were asked to provide information on the patient's county of residence during treatment. We analyzed this information in two different ways: a comparison of patients/survivors based on New Mexico's 5 Public Health Division regions and a comparison of rural vs. urban patients/survivors.

Comparison by NM Public Health Region

The New Mexico Department of Health's Public Health Division groups New Mexico's counties into the following five regions. For purposes of this analysis, we grouped respondents based on the patient's region of residence:

- Region 1: San Juan, McKinley, Sandoval, Cibola, and Valencia
- Region 2: Rio Arriba, Taos, Colfax, Union, Los Alamos, Santa Fe, Mora, San Miguel, Guadalupe
- Region 3: Bernalillo
- Region 4: Harding, Quay, DeBaca, Curry, Roosevelt, Chaves, Eddy, and Lea
- Region 5: Torrance, Catron, Socorro, Lincoln, Grant, Sierra, Hidalgo, Luna, Dona Aña, Otero

A map of the five Regions appears in Section 2.

Figure 44: Most Important Services by NM Public Health Division Region

PHD Region	Most Important Services	Average Importance	# Respondents
Region 1	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.72	108
	• Early detection/screening	3.69	110
	• Education on managing the cancer process	3.34	102
Region 2	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.69	61
	• Early detection/screening	3.61	64
	• Pain management/palliative care	3.35	57
Region 3	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.72	152
	• Early detection/screening	3.70	151
	• Education on managing the cancer process	3.39	141
Region 4	• Early detection/screening	4.00	5
	• Traditional medical treatments (e.g., radiation, chemotherapy)	4.00	5
	• Education on managing the cancer process	3.80	5
Region 5	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.73	64
	• Early detection/screening	3.72	65
	• Hospice/end-of-life services	3.61	41

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Region 5** respondents rated complementary/alternative therapies, assistance with legal issues, housing/lodging services, in-home care, training in at-home management skills, pain management/palliative care, and hospice/end-of-life services as significantly more important than other respondents did

Figure 45: Largest Access “Gaps” by NM Public Health Division Region

PHD Region	Services with the Largest Access “Gap”	Average Gap	# Respondents
Region 1	• Transportation services to/from medical appts.	-0.64	39
	• Financial assistance for non-medical expenses	-0.55	44
	• Financial assistance for medical expenses	-0.40	50
Region 2	• Financial assistance for medical expenses	-0.58	26
	• Assistance with insurance issues	-0.52	31
	• Assistance with legal issues	-0.52	21
Region 3	• Financial assistance for non-medical expenses	-0.65	48
	• Assistance with legal issues	-0.59	54
	• Financial assistance for medical expenses	-0.55	62
Region 4	• Early detection/screening	-1.00	4
	• Education on managing the cancer process	-0.50	4
	• Pain management/palliative care	-0.33	3
Region 5	• Emotional support programs for caregivers/family	-0.88	42
	• Assistance with legal issues	-0.76	29
	• Education on managing the cancer process	-0.70	43

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Region 1** respondents reported a significantly smaller access gap for assistance with legal issues and education on managing the cancer process than other respondents did
- **Region 5** respondents reported a significantly larger access gap for emotional support programs for patients, emotional support programs for caregivers/family members, pain management/palliative care, and education on managing the cancer process than other respondents did

Figure 46: Largest Quality “Gaps” by NM Public Health Division Region

PHD Region	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Region 1	• Transportation services to/from medical appts.	-0.46	24
	• Financial assistance for non-medical expenses	-0.42	33
	• Assistance with legal issues	-0.39	31
Region 2	• Education on managing the cancer process	-0.36	36
	• In-home care	-0.35	17
	• Information re: cancer-related services in NM	-0.31	32
Region 3	• Assistance with legal issues	-0.65	40
	• Financial assistance for non-medical expenses	-0.52	33
	• Financial assistance for medical expenses	-0.46	48
Region 4	• Transportation services to/from medical appts.	-3.00	1
	• Financial assistance for medical expenses	-1.50	2
Region 5	• Education on managing the cancer process	-0.81	37
	• Emotional support programs for caregivers/family	-0.76	25
	• Assistance with legal issues	-0.74	19

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Region 1** respondents reported a significantly smaller quality gap for education on managing the cancer process than other respondents did
- **Region 2** respondents reported a significantly smaller quality gap for financial assistance for non-medical expenses than other respondents did
- **Region 5** respondents reported a significantly larger quality gap for emotional support programs for caregivers/family members and education on managing the cancer process than other respondents did

Rural vs. Urban Patients/Survivors

For purposes of this analysis, we used the working definition developed by the Rural Workgroup of the NM Cancer Council:

- Urban: Residents of Bernalillo, Dona Aña, Los Alamos, Sandoval, Santa Fe, and Valencia Counties
- Rural: Residents of all other New Mexican counties

Figure 47: Most Important Services by Location – Urban vs. Rural

Location	Most Important Services	Average Importance	# Respondents
Urban	• Early detection/screening	3.71	273
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.70	271
	• Education on managing the cancer process	3.38	250
Rural	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.78	131
	• Early detection/screening	3.62	134
	• Pain management/palliative care	3.39	110

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Urban** respondents rated financial assistance for medical expenses, financial assistance for non-medical expenses, transportation services to/from medical appointments, in-home care, and training in at-home management skills as significantly less important than **rural** respondents did

Figure 48: Largest Access “Gaps” by Location – Urban vs. Rural

Location	Services with the Largest Access “Gap”	Average Gap	# Respondents
Urban	• Financial assistance for non-medical expenses	-0.64	89
	• Assistance with legal issues	-0.56	101
	• Financial assistance for medical expenses	-0.52	111
Rural	• Transportation services to/from medical appts.	-0.56	57
	• Financial assistance for non-medical expenses	-0.45	65
	• Financial assistance for medical expenses	-0.44	73

The following differences in access gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Urban** respondents reported a significantly larger access gap for early detection/screening than **rural** respondents did

Figure 49: Largest Quality “Gaps” by Location – Urban vs. Rural

Location	Services with the Largest Quality “Gap”	Average Gap	# Respondents
Urban	• Assistance with legal issues	-0.65	72
	• Financial assistance for non-medical expenses	-0.52	60
	• Financial assistance for medical expenses	-0.51	83
Rural	• Transportation services to/from medical appts.	-0.51	47
	• Assistance with insurance issues	-0.42	73
	• Financial assistance for non-medical expenses	-0.40	57

The following differences in quality gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Urban** respondents reported a significantly larger quality gap for early detection/screening services than **rural** respondents did

9. Comparisons to the 2002-2004 NM Cancer Services Survey

Differences Between the 2002-2004 and 2010-2011 Surveys

For this study, we made several modifications to both the sampling approach and the survey instrument we used for the 2002-2004 version of our New Mexico Cancer Services Survey.

Sampling Approach

For the current study, thanks to the statewide volunteer network we have developed, we were able to visit many more clinic locations around the state than we did in the earlier study. The 2002-2004 study was completed in two phases. During Phase I, two New Mexican cancer services organizations, People Living Through Cancer and the Prostate Cancer Support Association of New Mexico, assisted us in mailing survey questionnaires to individuals in their databases. During Phase II, we conducted on-site surveys at eight clinic locations throughout New Mexico, with an emphasis on collecting data from demographic groups that were under-represented during Phase I (e.g., uninsured/underinsured individuals and those outside of Bernalillo County).

The overall respondent demographics for the two studies are fairly similar. However, given that a large proportion of respondents in the 2002-2004 were clients of People Living Through Cancer and the Prostate Cancer Support Association of NM, it is likely that the original group had substantially more experience working with cancer services organizations and accessing emotional support services than the general population coping with cancer.

Survey Instruments

We added several new questions to the current survey instrument, to enable more in-depth evaluation of issues that arose in the narrative responses to the 2002-2004 study. In particular, we asked respondents to evaluate several cancer-related services in the 2010-2011 survey that were not listed on the earlier survey instrument, including:

- Assistance with legal issues
- Assistance with insurance issues
- Financial assistance for medical expenses
- Financial assistance for non-medical expenses
- Pain management/palliative care
- Education on managing the cancer process
- Information re: cancer-related services in NM

In addition, while the 2002-2004 survey asked participants to rate their satisfaction with a variety of cancer-related services, in 2010-2011 they were asked to rate their satisfaction with two aspects of each service: ease of access and service quality.

Comparison of Results from the 2002-2004 and 2010-2011 Surveys

Despite these differences, we made some interesting observations when comparing the results from the 2002-2004 study to the current survey.

- **Traditional medical treatments and early detection/screening services remain the two most important services** to survey respondents, and respondents continue to be relatively satisfied with both of these services.
- In both studies, respondents indicated a **gap between “importance” and “satisfaction” for every service** we asked them to evaluate.
- **Respondents continue to report substantial gaps in transportation services** to/from medical appointments. Transportation services had the largest satisfaction “gap” rating in the 2002-2004 study, and the largest “access” and “quality” gap ratings in 2010-2011 if we omit services that were not included in the earlier study.
- It appears that **patients/survivors and their loved ones are having more difficulty accessing needed services now than they did during our earlier study.** In the 2002-2004 study, 56% of respondents indicated that they did not have difficulty accessing services that they needed. In the current study, only 39% indicated that they did not have difficulty accessing needed services. In both studies, the number one factor limiting access, by far, was that respondents were not aware that the services they needed were available.

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10. Discussion

Key Findings and Implications

The New Mexico Cancer Services Survey yielded several important observations and implications about the experiences of New Mexico's cancer patients/survivors and their loved ones. Highlights include:

- **Medically-oriented services** (traditional medical treatments such as chemotherapy, radiation, and surgery; early detection/screening services) **were the most important services to respondents**, followed by informational/educational services (information regarding cancer-related services in New Mexico; education on managing the cancer process), and pain management/palliative care.
- Respondents were quite satisfied with ease of access and service quality for the two services rated as most important - traditional medical treatments and early detection/screening. However, **there is substantial opportunity to improve New Mexicans' experiences** with several other cancer-related services.
 - Services where respondents indicated the **lowest satisfaction with ease of access** included: financial assistance for non-medical expenses; assistance with legal issues; transportation services to/from medical appointments; complementary/alternative therapies; and emotional support programs for caregivers/family members
 - Services where respondents indicated the **lowest satisfaction with service quality** included: assistance with legal issues; financial assistance for non-medical expenses; complementary/alternative therapies; transportation services to/from medical appointments; and in-home care
- For each of the seventeen cancer-related services evaluated, respondents indicated a gap between the importance of the service and their satisfaction with both ease of access to the service and the quality of the service. **Services with the largest gaps may indicate the greatest opportunities for improvement.** These include financial assistance for medical and non-medical expenses; transportation services to/from medical appointments; assistance with legal issues; emotional support programs for caregivers/family members; and information regarding cancer-related services in New Mexico.
- It appears that **patients/survivors and their loved ones are having more difficulty accessing needed services now than they did during our earlier study.** In the 2002-2004 study, 56% of respondents indicated that they did not have difficulty accessing services that they needed. In the current study, only 39% indicated that they did not have difficulty accessing needed services.
- There appear to be substantial **opportunities to improve the way information is disseminated about New Mexico's existing cancer-related services.** Nearly 40% of respondents indicated they were unable to access needed services because they

did not know that services were available. Respondents indicated that nurses and physicians were the most helpful sources for providing information on what cancer-related services were available to assist them.

- Over 80% of **respondents indicated that they were satisfied or very satisfied with the level of communication/coordination between their different medical providers** (oncologists, surgeons, primary care providers, etc.). Areas for improvement included coordination between oncologists and primary care providers, and between oncologists and surgeons.
- There are **opportunities to refine service offerings to better meet the needs of specific underserved groups**. For example, patients aged 75 and over reported more challenges related to transportation to/from medical appointments than other respondents, and Southern New Mexicans reported a bigger gap in emotional support services than those in other parts of the state.

Next Steps

This report is being distributed to cancer services providers throughout New Mexico, in the hope that our findings will provide some guidance for how they might continue to improve the services offered to New Mexicans coping with cancer. It will also serve as a major input to Cancer Services of New Mexico's strategic planning process, to ensure our programs and services continue to be focused on the areas of greatest need.

Many of the areas identified for improvement in this report require further research before they can be effectively addressed programmatically. For example, while "transportation services to/from medical appointments" appears to have much opportunity for improvement, as it did in our 2002-2004 study, there are many questions that would need to be answered in order to develop programs to address this gap. These questions include: Are the major issues financial (e.g., insufficient funds for patients to cover gas costs) or logistical (e.g., patients unable to physically drive themselves to/from treatment)? Are they local (e.g., patients having difficulty getting back and forth to radiation appointments each day) or long-distance (e.g., patients traveling to Albuquerque for treatment from other parts of the state)? We would welcome the opportunity to partner with other organizations to answer these and other questions that emerge from this study.

There are many additional ways that we could mine the data in our survey database, and we would be happy to conduct additional analyses to assist others in answering specific questions not covered in this report.

Our experiences so far have given us tremendous hope that this study will positively impact the experiences of New Mexico's cancer patients/survivors and their loved ones. Throughout the study, we have developed interim reports for the many organizations that have collaborated with us on this program. These reports summarize data from clients of each partnering organization. In each case, the reports provided indications for changes the group could make to better meet the needs of its clients.

We hope you have found the information in the report to be of value. We welcome comments on this report, as well as on the value repeating the New Mexico Cancer Services Survey in the future. Please contact us at (505) 259-9583 or info@CancerServicesNM.org with your questions and comments.



Appendices

- Appendix A: Survey Questionnaire
- Appendix B: Comments on Services Where Respondents Reported Low or Moderate Satisfaction (Question 7)
- Appendix C: Comments on Factors Limiting Access to Needed Services (Question 8)
- Appendix D: Comments on Services That Did Not Exist to Support Respondents (Question 11)
- Appendix E: Comments on Services Respondents Would Like to See Improved (Question 12)
- Appendix F: Comments on Coordination/Communication Between Providers (Question 10)
- Appendix G: Additional Comments (Question 20)

Appendix A: Survey Questionnaire



The New Mexico Cancer Services Survey A statewide survey of cancer patients/survivors and their loved ones

Please take a few minutes to complete this confidential survey. All individual responses will be kept confidential. Summarized findings will be shared with providers of cancer-related services throughout the state, in an effort to improve New Mexico's cancer-related services. Questions? Contact Cancer Services of New Mexico at info@cancerservicesnm.org or (505) 259-9583.

Section I: Background

- | | | |
|--|--|---|
| <p>1. Your Relationship to the Cancer Patient</p> <ul style="list-style-type: none"> a. Patient/survivor b. Spouse/significant other c. Parent of the patient d. Child of the patient e. Other (describe) _____ | <p>2. Current Status of the Cancer Patient</p> <ul style="list-style-type: none"> a. In active treatment (e.g., chemo, radiation) b. Not in active treatment – in remission c. Not in active treatment – not in remission d. Deceased e. Other (describe) _____ | <p>3. Year of MOST RECENT diagnosis _____</p> |
|--|--|---|

Section II: Your Experience with Cancer-Related Services in New Mexico

For each service listed below, circle the appropriate responses to questions 4, 5, & 6.

Rating Scale

- 1. Low
- 2. Moderate
- 3. High
- 4. Very High
- NA Not applicable/No opinion

	4. Rate the <u>importance to you</u> of each of these services:	5. If you or your loved one <u>needed</u> this service, please rate your <u>satisfaction with ease of access</u> to this service:	6. If you or your loved one <u>used</u> this service, please rate your <u>satisfaction with the quality of service</u> you received:
a. Early detection/screening	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
b. Traditional medical treatments (e.g., radiation, chemotherapy, surgery)	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
c. Complementary/alternative therapies (e.g., herbs, acupuncture, meditation)	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
d. Emotional support programs for patients	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
e. Emotional support programs for caregivers/family members	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
f. Assistance with legal issues	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
g. Assistance with insurance issues	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
h. Financial assistance for medical expenses	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
i. Financial assistance for non-medical expenses	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
j. Transportation services to/from medical appointments	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
k. Housing/lodging services (if treatment occurred away from home)	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
l. In-home care	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
m. Training in at-home management skills (e.g., administering medication)	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
n. Pain management/palliative care	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
o. Hospice/end-of-life services	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
p. Education on managing the cancer process	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
q. Information re: cancer-related services in NM	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA
r. Other (describe) _____	1 2 3 4	1 2 3 4 NA	1 2 3 4 NA

7. Please comment on any services where you circled "Low" or "Moderate" satisfaction in response to Questions 5 or 6.

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Section II: Your Experience with Cancer-Related Services in New Mexico (continued)

8. For those services where you indicated Low or Moderate satisfaction with ease of access in Question 5 what, if anything, limited your access to these services? (circle all that apply)

- a. Cost – too expensive/could not afford
 - b. Enrollment requirements (other than cost)
 - c. Was not aware services were available
 - d. Other (describe): _____
 - e. Not Applicable - did not have difficulty accessing services
- Comments: _____

9. How helpful were each of the following in providing information on what cancer-related services were available to assist you and your family/loved ones?

1. Not helpful 3. Helpful NA Not applicable/No opinion
 2. Somewhat helpful 4. Very helpful

a. Physicians	1	2	3	4	NA	e. Cancer agencies/ organizations	1	2	3	4	NA
b. Nurses	1	2	3	4	NA	f. Independent reading/ internet searches	1	2	3	4	NA
c. Social Workers	1	2	3	4	NA	g. Other (describe): _____	1	2	3	4	NA
d. Cancer support group(s)	1	2	3	4	NA						

10. How satisfied were you with the coordination/communication between different medical providers (oncologists, surgeons, primary care providers, etc.)? (circle one)

- a. Not satisfied
 - b. Somewhat satisfied
 - c. Satisfied
 - d. Very satisfied
 - e. Not Applicable/No opinion
- Comments: _____

11. What cancer-related services do you need now that don't exist to support you?

12. What cancer-related services would you want to see improved? How would you improve them?

Section III: Demographic Information

13. Type of Cancer at MOST RECENT DIAGNOSIS
- a. Breast
 - b. Colorectal
 - c. Leukemia/ Lymphoma
 - d. Lung
 - e. Ovarian
 - f. Prostate
 - g. Other (describe) _____
14. Insurance Coverage (during treatment) – circle all that apply
- a. Medicaid
 - b. Medicare
 - c. Medicare Supplement
 - d. Private – HMO
 - e. Private – PPO/POS
 - f. Private – Indemnity
 - g. TriCare
 - h. Self payer/No insurance
 - i. Other (describe) _____
15. Patient's Gender
- a. Male
 - b. Female
16. Patient's Age at MOST RECENT Diagnosis
- a. Under 35
 - b. 35 – 54
 - c. 55 – 74
 - d. 75 or Older
17. Patient's Ethnic/Racial Group – circle all that apply
- a. Hispanic
 - b. Non-Hispanic White
 - c. Black
 - d. Native American
 - e. Asian
 - f. Other (describe) _____
18. Patient's COUNTY of Residence: _____
19. Oncology Group or Hospital: _____

Section IV: Other Comments

20. Is there anything else you would like to add?

Thank you for taking the time to complete this survey!

Appendix B: Comments on Services Where Respondents Reported Low or Moderate Satisfaction

Summary of open-ended responses to Question 7: “Please comment on any services where you circled ‘Low’ or ‘Moderate’ satisfaction in response to Questions 5 or 6.” Responses have been organized by type of cancer-related service.

A. Early Detection/Screening (13 comments)

- Early detection was not provided
- Dept of Health BCC not well publicized - BCC provider does not return calls. WHS - 6 mo. wait for appt. - promised to call back but didn't.
- In Nov. 2009 patient was told he might have cancer but was not diagnosed until January. By then it had spread and enlarged quite a lot.
- Early screen advocacy has to be emphasized in Indian Health Service units; it's always delayed or late
- Early detection - saw primary care physician several times for shortness of breath and had X-rays but condition was not diagnosed for 1 year.
- When I was very ill for more than 1 year, I didn't receive proper treatment and diagnosis
- Cancer could have been detected earlier if doctors (PCP) had paid attention to symptoms.
- I went for all preventative pap tests. Every time was negative. Then I was stage 4, too late. Why was cancer never detected early?
- I had no insurance, couldn't afford pap smear.
- I was not taken seriously, when they finally did, I was at stage 4!!!!
- Mammograms do not catch cancer sometimes. We need better early detection
- My regular provider did not detect this cancer. I had to go to a private doctor. I find this hard to understand
- There was no early detection

B. Traditional Medical Treatments (16 comments)

- This facility has sub-standard physicians, oncologists, surgeons, and preventive care. They remove tumors without following basic protocols (i.e., does not even check sentinel node). The entire protocol and continuum of care needs to be investigated for malpractice.
- Relying on CEA only is very bad
- The doctor suggested waiting 6 months. Received no prep for recognizing congestive heart failure. I was alone throughout chemo.
- Radiation machine broken 3 out of 6 visits
- Radiologist (now deceased) was rather disinterested in me as a patient
- Chemo made me violently sick and I spent 15 days in hospital. I will never have chemo again
- Long time to see the oncologist
- Very poor care in hospital
- Refused services until cancer had metastasized
- Bone marrow transplants need to be done here
- Diagnostic procedures, waiting time at this clinic is very long. Appointments are also hours late.
- Don't have information on comparing success rates, per type of cancer, among providers in NM (ie UNM vs Lovelace vs Presbyterian vs others).
- I would like my PCP to order preventative tests.
- My original doctor left at the same time my primary care doctor left and the change was somewhat troublesome.
- There should be more than one doctor in clinic at all times. Wait for chemo is sometimes far too long.
- Have not been satisfied at all with treatment and/or obtaining outside assistance.

C. Complementary/Alternative Therapies (11 comments)

- Discontinued homeopathic therapy on doctor's advice, as not really being effective treatment.
- I don't know much about alternative therapy
- I like alternative therapy but am not comfortable with healing ability with a new cancer patient.
- Alt therapies - not effective in my experience w/ others who have had cancer and died. You can only eat so many bushels of carrots or take shark pills before you see that they are ineffective therapies
- Not told of any complementary/alternative therapies available
- Complementary medicine was never offered and it was discouraged.

- Not interested in alternative treatment.
- Alternatives never offered/discussed.
- Wanted acupuncture, but couldn't afford it.
- No alternative therapies have been offered or advertised
- Not into herbs, etc.

D. Emotional Support Programs for Patients (10 comments)

- I was completely on my own and was even divorced by my husband because of all the stress involved.
- No one offered emotional support.
- No counseling available for patient
- No counseling available for family
- I'm finding that I need more emotional support now and after everything.
- Not receiving emotional support
- Not involved in any support program.
- I believe the emotional support programs are quite limited.
- Work with a support group
- Volunteer w/ doctor's office frustrated patient at initial consultation, so patient no longer pursued emotional support services.

E. Emotional Support Programs for Caregivers/Family Members (4 comments)

- No emotional support for caregivers & family members in our area
- Info needs to be as available and direct as that for patient home care
- I'm finding that my caregiver needs more emotional support now and after everything.
- We are looking for an ovarian cancer support group that caters to couples

F. Assistance with Legal Issues (2 comments)

- Need more legal assistance
- Low access score for legal services due to lack of knowledge service was available

G. Assistance with Insurance Issues (6 comments)

- I received no information on where I might find assistance on insurance or any other type of assistance.
- Only single-payer health care will straighten this out!
- Our insurance provider and the cancer center are not on the same page when it comes to billing. We need help.
- I'm not aware of any service that would help with the insurance company that authorizes my short-term/ long-term absences from work. Our HR dept. is useless and even a letter to the insurance company's CEO was ignored. I could use help!
- It seems impossible to get the relevant information to determine whether Medicare will pay for cancer drugs -- so one can't choose to switch from private ins. even though eligible for Medicare.
- Gap/short term disability insurance and paperwork a living hell. There is a need for advocates/mentors to guide patients.

H. Financial Assistance for Medical Expenses (10 comments)

- Under new rate from health plan - unknown amount
- It's all so much money, and Medicare sucks. Insurance should not turn down for pre-existing condition
- I didn't know of these programs.
- Lack of easily accessible funding for treatment and procedures necessary for proper therapy
- Low access score for financial services due to lack of knowledge service was available
- Due to anticipation of losing private health insurance have sought financial assistance.
- No financial help available while unemployed.
- We received very little help with insurance co-pay assistance.
- I have called the patient navigator with no success. I've applied to Social Security, because Medicaid is cut off. If I were Mexican I could probably get it.
- Clarify difference in Medicare payment decisions from state-to-state, region to region

I. Financial Assistance for Non-Medical Expenses (6 comments)

- Unemployed - turned down for assistance due to past income.
- Low access score for financial services due to lack of knowledge service was available

- I tried to get financial assistance for wigs but none was offered.
- I didn't know of these programs.
- I think everyone needs help affording their cosmetics, cleaning products, laundry detergent, etc
- I got a book from a TV commercial - What to Eat During Chemo - then found out it is available through a cancer services organization. I wrote them and they told me I would have to buy the book. They should give us something for free.

J. Transportation Services to/from Medical Appointments (10 comments)

- No transportation in our area
- Did not know transportation was available
- Transportation is an issue.
- Transportation denied because we have a car
- Living in a smaller city. Time limit on ride services for appointments.
- Transportation is a concern because we live about 60 miles north of Santa Fe, so we drive every day.
- Efforts to arrange transportation for out of town care was very difficult.
- I live out of town & chose to come to this clinic. I was unable to use transportation.
- Not receiving transportation services.
- Transportation-hard to arrange and not available at times needed to get to appointment

K. Housing/Lodging Services (4 comments)

- Efforts to arrange lodging for out of town care was very difficult.
- I had my surgery in Houston and no one stepped up to help find housing.
- Availability of services for out-of-town patients is non-existent.
- I needed information on motel/hotel accommodations during time in Albuquerque for radiation therapy - need information on affordable places to stay.

L. In-Home Care (4 comments)

- No in-home care in our area
- I had NO nursing care after my surgery.
- Aid to help the patient at home was not available to us and it should have been made available to us
- Caregiver came for two visits - didn't wash hands, not professional, talked down to us, so we stopped

M. Training in At-Home Management Skills (2 comments)

- Need classes for home care givers if non-professionals
- Could have used info on administering meds.

N. Pain Management/Palliative Care (4 comments)

- Incision pain from surgery continuous - no pain med, rx.
- At the time, nausea medication was really inadequate.
- I didn't like oxycotin for pain as much as tylenol.
- About pain - not too much attention, they just say go to exercise, yoga, tai chi. That works for me but others complain about pain.

O. Hospice/End-of-Life Services (0 comments)

P. Education on Managing the Cancer Process (8 comments)

- There was no education on managing the cancer process that I can recall
- Need knowledge on how to proceed.
- Too haphazard; getting information in doctors office doesn't necessarily mean you have learned what you need to know
- Did not receive this outside of initial orientation of chemo
- There was not enough qualified staff to help. No one seems to have the right information.
- The education for patient families was not available to us and it should have been made available to us
- At the time of my treatment not much information given.
- Never really received information as the process went along

Q. Information re: Cancer-Related Services in NM (11 comments)

- Have not received much info on any services

- Didn't need or use any other services.
- I have been too sick and tired to deal with all the info people want to give me.
- Most services were not mentioned until later on.
- Have not been offered these services yet
- It would have been nice to have known about this group 3 years ago.
- Esophageal cancer - we have found NO services to aide us in any way!!!
- We didn't know these services were available.
- Didn't know about most of these services. I am from Santa Fe and have been treated there.
- Don't know enough. Have services -- but would like others to have.
- No information freely given

Other Comments

Concerns/Issues

- Help just isn't there
- No one helps us
- We live in Reserve and access is limited because of distance from Silver City

Compliments

- Excellent treatment, advice, and service by my doctor took care of my problems.
- Overall, we received great care once we were past the initial diagnosis.
- All services provided have been excellent
- Everything is going good.
- I've never had a bad experience.
- Everyone has been great
- Brochures/information on cancer very helpful.
- Emotional support group/faith in Christian beliefs helps
- Satisfied
- Satisfied with care here. Not satisfied with care at another clinic.
- I hate that I have to come here but I love the help and treatment I get. God bless this people and place.
- There has been a lot of improvement (my 2's) since 2007.
- I am very satisfied with how much kindness and professionalism everyone has displayed
- Best care for my sister.
- For early service I am pleased but can't respond in-depth
- We found affordable lodging with all of the amenities we needed.
- The services here have been very, very nice - thank you
- I have had the best of care
- We were happy with the services we've needed. We haven't needed some of the services
- I had 2 excellent dr.'s

Services Not Needed/Used

- It is too early in my treatment to be able to accurately assess and rate many of the items.
- My cancer is not in the stage that most of these services would be offered at this time
- I am on my 5th chemo treatment and have not needed many of the cancer services yet.
- Did not need or use services.
- We're more comfortable getting emotional support from our family.
- Wasn't needed
- There were no legal issues.
- Medicare paid insurance.
- I don't require a lot of educational support for cancer treatment because I've been through this before.
- All the low numbers are because I haven't used those programs.
- Treatment has not begun yet
- Financial help was not necessary. Wife is a RN and daughter is a PA
- Most not applicable
- Her cancer was detected early and is very manageable with the treatment she is receiving. So, our need of outside

services is not great. Thank you.

- Services not necessary at this point.
- We haven't needed help yet. Caregiver hasn't reached out to a support group yet.
- Didn't use most of this.
- I was diagnosed at a very early stage. I had surgical removal of portion of lung and that took care of it.
- Some were not pertaining to me
- It was unnecessary to use lodging/housing. I sought no other info about other services.
- I haven't used any of these services.
- Hopefully the surgery will cure cancer with no need for additional care.
- I haven't had to use this service
- We are from CT. Did not require all services listed above since we have support system at home.
- Do not expect at this time to have to go out of state
- Services not needed at this time, and have not received services from here yet
- My family took care of many of these items - they were not issues that I needed to have addressed.
- Do not need transportation assistance
- My wife doesn't drive, uses taxi.
- Spouse had lumpectomy and visiting nurse helped for 1 week.
- I think my parents are doing OK in their house.

Appendix C: Comments on Factors Limiting Access to Needed Services

Summary of open-ended responses to Question 8: “For those services where you indicated Low or Moderate satisfaction with ease of access in Question 5 what, if anything, limited your access to these services?” Responses have been organized by factor limiting access.

A. Cost – Too Expensive/Could Not Afford (7 comments)

- Cost of complementary treatments
- Very little financial resources.
- Financially it's difficult to have treatment for pain. I think one learns to use alternative meds, and it works
- Cannot afford alternative treatment
- Transportation costs and housing costs, for radiation
- Need help with large co-pays.
- I can't afford to hire an attorney to deal with my insurance company - and I really need one

B. Enrollment Requirements Other Than Cost (6 comments)

- Did not qualify
- Did not qualify
- Did not qualify
- Transportation denied - have a car, but could not pay for gas
- Cannot enroll for Medicaid;
- Medication provided in Arizona was not approved in New Mexico

C. Was Not Aware Services Were Available (9 comments)

- Was not aware of mileage reimbursement until this year.
- No info given
- No information. Medicare is a catch 22 regarding oral cancer drugs.
- I was told I could get paid added income as I can't work, but I got no info on how to do so.
- It was unknown to our mother and their cultural sensitivity sometimes causes barriers
- Medicare/Medicaid benefits were not explained
- I was not aware that there were counseling services available specific to patients and their families who have had cancer.
- Services are not available for patients in Las Cruces
- Need to know who to call

D. Other (33 comments)

Timing of Diagnosis/Availability of Medical Services (12 comments)

- Several doctors couldn't figure it out
- My ob/gyn outright refused to refer me to another facility for biopsy (I have this in writing)
- Too long to get reasonable appointment and accepting physicians.
- Not having a proper read on mammogram. This needs to be improved
- I was mis-diagnosed - from perfect to stage 4 cancer 3 weeks later
- I had a long wait (a month) when I needed a psychologist
- The medical system is broken and no one seems to care
- MD delayed diagnosing
- Appointment and consult times very far apart. Treatments were slow in coming. Appts. were often hours late and many weeks apart.
- I believe these should be provided in such a way that choice of providers is universal
- Prolonged wait to schedule surgery
- I found my own even though I had seen the doctor the week before

Transportation/Travel Issues (9 comments)

- Mostly transportation and never have enough expense to travel out of town.
- Not enough methods of transportation.
- Distance prevents access

- Hard to get family and friends to drive me and stay with me when needed
- Gas costs, traveling often in the winter months
- Transportation - those I checked were not available to Medicare (primary insurance) patients
- Out of town patient-too much driving to come back to ABQ again.
- Transportation - wheelchair access, too much paperwork, not available at needed times, not late enough.
- At time I was diagnosed there was no cancer center in Gallup so it was stressful to make frequent trips to Albuquerque - things would be different now

Other Issues (12 comments)

- Support groups don't last.
- The seminars often take place in the evenings - too exhausting for me
- Was at MD Anderson in Houston - training was cursory, did most of housing on my own
- Need OT, exercise program
- I had to go on my own for alternative therapies.
- There was only one employee who understood insurance & she was great but hard to get ahold of. Others gave wrong info, were rude and indifferent.
- Need help when it comes to the billing department and the insurance provider. I am being billed for things that the insurance should pay
- Scheduling, info
- Better training for in-home svcs people - perhaps clinic should staff their own
- Need access to personnel to answer questions
- No info provided
- Too late in process

E. Did Not Have Difficulty Accessing Services (26 comments)

- I have insurance that paid very well
- Wasn't interested
- We have a program to pay for services
- Once I got out of the initial medical system I felt there is some hope
- Majority of the nursing staff was very caring
- Have not needed care yet
- I have insurance that covers everything
- Have medical insurance
- Did not need service.
- We have a cancer center here and it is excellent. Nurses and staff are excellent.
- Didn't need them
- A urologist did my first kidney cancer and while on hold on phone I learned about support and got to see a cancer doctor
- I have just not reached out yet. Need to.
- Have not had to look into yet
- I like where I am living each day
- Did not need or did not use state services
- Most questions are premature. It's too early for me to need/evaluate these services.
- Everything was satisfactory.
- Services weren't needed
- Too early to tell
- We did not require the services
- Have not needed those services
- Spoke with person at cancer center - very good at explaining
- Did not require services beyond Medicare & secondary insurance
- I was very happy with ALL services
- Just didn't require services yet

Appendix D: Comments on Services That Did Not Exist to Support Respondents

Summary of open-ended responses to Question 11: “What cancer-related services do you need now that don’t exist to support you? Responses have been organized by type of cancer-related service.

Financial Assistance (15 comments)

- Financial aid to facilitate the best treatment methodologies rather than taking secondary/substandard pathways for treatment.
- Financial help
- Affordable medication
- Financial help
- Financial support and insurance guidance
- Financial support
- Support, assistance with finances with cancer.
- Financial help so I am not a total burden on my family.
- An advocate to help with STD issues.
- Information on help with bills
- Financial help to effectively apply to state for SSI aid.
- Cost of medications per Medicare questionable
- Help get my wife her SS Supplement income
- Help to supplement income from loss of job. Would have liked to have someone call me during recovery and help with questions and referrals.
- Wife should be compensated for caring for me, like Colorado/Arizona

Information/Education (13 comments)

- Not aware of what's available
- Information to know what to expect ahead
- Doctors do not give adequate information
- Where do we go post cancer treatments and after studies?
- Can't say - have never been referred to any services
- Education on Myeloma
- Don't know what may be available
- Don't know what is available.
- I would like to see an on-line blog or message board for local patients.
- Statistical data on CLL
- Have no idea, no info offered
- Just need their names and their services
- Research data on the offered drugs given in a layman's terminology, and the long term effects.

Emotional Support Services (12 comments)

- Emotional support
- Support group
- Support group that is well run/informative
- Emotional support
- Not being able to go to group/support groups during my treatments.
- Don't know, as a caregiver, I need to find a support group.
- We haven't found a support group that has husbands and wives - it's women only
- Groups
- Contact with other cancer patients
- I need to join a cancer support group.
- Support group for my children - ages 12-15 years
- Training for male spouses of cancer victims on the emotional condition of patient

Transportation Services (10 comments)

- Transportation
- There is no transportation for people who live in the rural areas of Grant County - Lake Roberts, Mimbres, Hanover, Cliff, Faywood, San Lorenzo, etc.
- Transportation,
- Possibly transportation. It gets tiring to drive every day. We have animals that require daily care.
- Transportation or financial aid
- Affordable transportation
- Transportation from Las Cruces to Albuquerque for treatment and other services.
- None now - needed transportation during chemo
- Transportation cost
- Transportation (out of county)

Research/Treatment Protocols (8 comments)

- Neuropathic support services due to copper deficiency
- Local clinical studies
- Better local options for reconstruction with breast cancer
- To have pump disconnection available here in Las Vegas in order to prevent traveling to Santa Fe, 1 hour to and from, just to have this done.
- Clinical trials available to those who are post-treatment
- Bone marrow transplants
- Access to 1) Clinical studies/trials with PLX4032/RO5185426. 2) Stereotactic body radiosurgery
- Proton treatments

Assistance with Day-to-Day Management (5 comments)

- Help (before hospice) at getting equipment for personal use such as wheelchair, walker, medical bed, bedside potty seat, etc.
- Help in obtaining a wig or head covering.
- Housecleaning, yardwork, grocery shopping
- Housekeeping help during chemo.
- Family education for patient home care

Insurance Assistance (4 comments)

- No one knows who should know info on insurance/medicare, for financial decisions. Have to search Internet.
- Outrageous co-pays
- Access to Medicaid is blocked unless you're not from here.
- Help with insurance company

Alternative/Integrative Therapies (3 comments)

- Alternative medicine
- Alternatives, herb, massage, etc.
- Accupuncture, etc.

Coordination of Care (2 comments)

- Intermediaries between providers.
- Coordination between oncology drs. and primary care providers

Other Services That Did Not Exist to Support Respondents

- A Native American cancer outreach in NW New Mexico such as UNM Native American Cancer Center - to educate/assist in a culturally sensitive approach
- Occupational therapy/exercise program
- Counseling - esp. in nutritional issues, etc.
- Nutrition
- Cancer social workers
- Meds
- Patience by surgeon

- Everything is good, but could be a bit quicker in assisting with metastatic cancer care.
- Getting in to see your doctor when you need to
- Patients to be referred to Gallup clinic for treatment

Comments re: No Additional Services Being Needed

- Everything is OK
- None – completely satisfied
- None – very satisfied.
- None. I thought chemotherapy and radiation improved my health.
- None that I am aware of
- None – all services are at this clinic
- I can't think of any
- No current needs

Appendix E: Comments on Services Respondents Would Like to See Improved

Summary of open-ended responses to Question 12: “What cancer-related services would want to see improved? How would you improve them?” Responses have been organized by type of cancer-related service.

Information/Education (23 comments)

- More and better information at doctor's offices regarding cancer information and care and organizations for assistance once diagnosed.
- More information to people about how to initially access cancer-related services. I came on it accidentally
- More information
- More info on what is available and how to access this information.
- More information at beginning
- Public is not informed about who can help them with issues that cancer patients have
- More info for families that need help.
- Informational meetings that cover patients services. These meetings should occur as part of the patient's doctor appointments
- General info or list of services available. Try a mailing list to inform patients of the different programs and dates and times and locations
- No knowledge of what is available and where they are.
- Need person who would just answer questions for patients and caregivers- toll-free number to call for information.
- At diagnosis - too shocked to absorb info/options. Need time to take it all in.
- Prepare patients as to what to expect. Tell if someone can come to the home.
- Access for medical questions/issues
- I just need to get more info re: emotional support services and possibly financial assistance info
- Information on how to pay for treatment, especially the ORAL expensive drugs. PUBLISH the info.
- Information concerning different doctors and surgeons
- More prominent information regarding side effects of medication. They can be very helpful - and make decisions on whether or not to seek chemo much more reasonable. We were shocked to find out how very tolerable the chemo regimen is.
- To explain to Native American patients more about cancer
- Education of your particular cancer. Hire someone that is interested in teaching.
- What to expect as treatment progresses. Physicians are busy. Brochures for each type of cancer?
- Education for early detection - media
- Patient and family education for home care

Communication/Coordination of Care (13 comments)

- Better referral system for oncology
- A cancer coordinator at all physicians/oncologists who routinely contact patients and family to address concerns, etc.
- An independent patient navigator to coordinate medical services. Breastlink (CA) model.
- Teamwork - I don't know how people are expected to manage their appointments when they aren't told about them.
- How to communicate with physicians
- Communication by physicians
- Communication
- More communication - less politics
- Appointments, lack of communication
- Scheduling
- Scheduling, information
- Some sort of coordination with the employers to arrange different schedules, remote working, etc..
- More interpreters - e.g., Navajo

Improved Treatment Facilities/Personnel (10 comments)

- All - this facility has sub-standard physicians and facilities
- This hospital needs better trained MDs
- An ER for cancer patients only

- Doctors in Albuquerque to think more of patient's needs
- Radiology attitude
- Social worker who does not value a patient's privacy should be reprimanded and possibly replaced
- The person who takes care of the assistance program at this cancer center has never been any help to my wife's situation.
- Better radiological readings with follow-up when possible questions occur and sooner than 6 mos. follow up.
- Equipment needs upgrading. Several breakdowns
- Newer equipment for radiation therapy

Transportation/Lodging Services (9 comments)

- Transportation
- Transportation
- Transportation for those in need.
- Transportation expense
- Transportation for the elderly/out of town patients
- Transportation to and from cancer center
- Time on car service to know I'm going to be home and not left behind because of other people's appointments in the way.
- Out of town patients need to know on low cost rooms, need to know if any transportation is available besides trains, bus, or taxis.
- Help with transportation/lodging for out of town treatments. More info on how to find.

Research/Treatment Protocols (9 comments)

- To have available different chemo options for cancer patients, besides being offered the options available through a trial program, which has a deadline.
- Updating options for care as treatment progresses.
- I believe stem cell should be used in the USA. They can grow organs to replace the bad ones.
- More options with chemo and clinical trials
- The care received in hospitals - clean and sanitize the facilities so people do not get infections
- Medications should work better
- Get rid of cancer.
- Cure for my ovarian cancer. Government could quit spending money for outer space and use for research
- Finding a cure

Access to Medical Personnel/Improved Service Times (8 comments)

- Provide more alternatives/doctors
- The time spent waiting in doctor's office - don't over-schedule.
- Less waiting time to be seen by physician. An additional physician/oncologist would certainly help (fewer complaints by patients who wait 2-4 hours to be seen by the doctor).
- Lab work needs to be more timely. Need to have more chemo nurses.
- Faster lab results and test results
- The time of month to see the Dr., they were not here on time.
- Appointments - the wait to check in, get bloodwork, see the doctor
- Waiting time, staff

Insurance Assistance (7 comments)

- Understanding of payment/insurance charges. Use Medicare payment structure as a model - allowable charges/no balance billing, etc.
- Insurance/legal
- Better coverage for those who don't have the insurance support we have
- The ways the insurance companies or clinics come after you -- they all want their money in under a year. Give us a break!!
- Insurance pay claims quicker
- Everyone diagnosed with cancer should automatically qualify for assistance and alternative medicine and physicians should be included in coverage.

- Improvement in availability of cancer curing drugs. Attention to pancreatic research.

Early Detection/Screening (6 comments)

- I did what I was supposed to do for early detection (i.e., mammograms) and was still at Stage III
- Better early detection
- Early detection of lobular cancer
- Early detection. PC doctors need to pay attention to symptoms.
- Pre-screening for younger people
- Early diagnosis for ovarian cancer - i.e., ultrasounds

Emotional Support Services (4 comments)

- Counseling for survivors and their families. It would be helpful if this information was distributed to the patient at office visits (i.e. at the oncologist's office).
- More caregiver groups. Could only find one which I couldn't attend on the night they met. Need more choices
- Cancer support group in my area - T or C.
- More support

Financial Assistance (4 comments)

- Make medication affordable
- More money allowed for cancer treatments allowed in SCI Medicaid.
- Financial/legal
- Help in paying for a wig

Nutritional Services (4 comments)

- Food and assistance with feeding. Less hoops for the already sick to navigate.
- Dietary assistance.
- Help on what foods we should stay away from, and what is good for us, also vitamins if any
- Patient food needs a lot of improvement.

Pain Management/Palliative Care (3 comments)

- Pain management
- Medications - improve for pain, nausea
- Pain Management

Other Services Respondents Would Focus on Improving

- Better publicity for BCC program.
- Alternative medicine would be better if it was cheaper!
- I would like to get the word out about ovarian cancer. It's better but we need more to get it earlier.
- Medicines
- I don't have a problem with the doctors; they have been fine. It's the peripheral services that need improvement.
- Learn, listen, reach out to others, that need help

Other Comments

Compliments

- Everything was there when I needed chemo, radiation treatment
- Fine to this point
- Great job
- So far we have had wonderful care.
- So far our services have been outstanding
- Everything is fine
- Navigator Program is outstanding.
- So far everything has been A1
- None at this time - everyone was so kind.
- All services are the best in the state
- All seem very good

- Very happy
- I think you all do a great job. Thanks to God and all the staff at my clinic I am cancer free now.
- All excellent
- None - everyone is kind and helpful
- I can't think of any.

General Comments

- Not enough experience to comment
- Don't know
- Don't know
- Don't know
- I'm not sure

Appendix F: Comments on Coordination/Communication Between Providers

Summary of open-ended responses to Question 10: “How satisfied were you with the coordination/communication between different medical providers (oncologists, surgeons, primary care providers, etc.)”

Positive Comments

- We are satisfied - thank you.
- Very satisfied - communication/coordination good
- Very satisfied!
- Very satisfied with all the providers we deal with, especially my PCP
- Excellent coordination
- Excellent communication
- Excellent!!
- It could not have been better
- This clinic has been the best
- I have been very satisfied with everything - doctor & cancer center
- Very organized and coordinated!
- All were most pleasant
- Great staff
- They were all on the same page
- They talk to each other
- Complete flow of info
- They tell what's going on
- They seemed to work very well together
- I have a whole person oncologist, meaning the body and mind
- I loved my oncologist and radiation physician. They did everything to make me feel good and special.
- Communication between Los Alamos and Houston seemed to be excellent
- My husband's team of doctors has been incredible
- My surgeon and urologist are very helpful
- Our present oncologist is wonderful. We will request that he communicate with primary care physician.
- The word cancer is scary to begin with, so it was good that every procedure, medication was explained and what to expect.
- Radiation and hematology worked together very well
- They all worked together to help me through it all. I'm not done yet - I have approx. 9 mos. of Herceptin and two weeks of radiation to go
- The doctor is the only doctor that has helped me and is so caring for my condition.
- Our doctor and the nurses have been amazing during the treatment.
- Every one of my doctors & nurses have made treatment & care easier. God bless everyone dealing with cancer and all the doctors treating it.
- My doctors made a great team. I felt so cared for.
- I thought my gynecologist was very helpful and understanding. He told me about an appointment at this clinic.
- It was all well done when this system, hospital, & doctors was still in place.
- My doctors in Santa Fe and Albuquerque had good communication with regard to my treatment
- From dr's on down to scheduling, very, very satisfied
- The professionalism and coordination efforts are remarkable. You truly care.
- Oncologist is outstanding. The infusion staff is outstanding
- All my physicians stayed in touch and continue to do so
- We received excellent care and treatment because of their communication
- I am very satisfied with the coordination/communication because there are a lot of people to coordinate and then remember to communicate to me
- My doctors are the best! Most everyone at this cancer center has been a pleasure.

Negative Comments

General comments about lack of coordination/communication

- No communication between doctors
- The never seem to converse with each other
- Doctors need to visit with each other a little more.
- The doctors don't communicate with each other and a lot of communication gets lost in the process
- Would like to see more real communication between all the different specialists and experts
- Communication among providers is lacking at times.
- It seemed they frequently hadn't talked to each other.
- Contradict each other
- Seems at times no one knows what is going on
- The doctors don't communicate with each other
- Did not communicate about my condition - was checked, but not checked fully especially since I had cancer already
- Hospital has a hard time sending info to other facilities.
- Not adequate communication - you must watch your own health issues!
- We stayed on top of most of this ourselves
- Very poor - had to make sure everything got scheduled myself.
- No explanations provided as to tests performed, results, etc.
- Could be improved
- It seemed it could have been more efficient.
- Each oncologist has a different opinion/plan of care.

Comments about coordination/communication with surgeons

- I would expect oncologist to be more in lead of surgical oncologist, radiation oncologist. Our oncologist seems to be on the side line.
- Seems like between my doctor at cancer center and urologist some info is lost
- Surgeon and oncologist sometimes had no communication
- Coordinating care between surgeons and reconstructive surgeons is difficult.
- Waited three months for surgery. No communication between doctor and surgeons.
- Although surgery turned out not to be an option coordinating all of the surgeons was very difficult
- I had my surgery in Houston and phone calls & medical records were not easily passed back and forth. I was satisfied w/ communication within my local group.
- Was sent to a surgeon w/o being fully informed. Surgery was done w/o biopsy and then required a second surgery
- Communication from my surgeons was very poor. All others have been excellent.
- No surgeon

Comments about coordination/communication with Primary Care Providers

- Sometimes physicians (primary/specialists) do not communicate together on a treatment plan, leaving it up to the patient to communicate to all parties!
- My PCP wasn't always informed on a regular basis.
- Would like to have primary physicians more involved
- Primary provider and cancer center doctors in my case don't communicate - my info doesn't go to Primary
- Would have liked my primary to know more about what went on when it was happening
- Oncology records were not sent to former primary care provider for more than 4 months. When they finally sent the records to my new primary care provider I had moved to a new primary care provider

Other comments

- Slow response
- It could be more personal
- When a person comes in new they need to know it is an all day affair so they will know what to expect.
- Some were scheduling cross-communications
- Have not seen oncologist we were assigned to yet - 5 weeks into treatment. Will see him 5 days before treatment ends for the first time
- The only problem was I wanted chemo in Oct. 2009 but the physicians wanted me in a study. This held everything

up and cancer came back with a vengeance

- Triage phone nurses should put themselves in our shoes
- The follow up questions I had were not answered in a timely manner because of understaffing.
- My insurance company is very difficult to deal with
- There is no sense of being treated as a whole patient. Each physician seems to feel more comfortable with their part

Mixed Comments

- So-so
- Pretty good
- Too early to tell
- We are just in the beginning stages of treatment
- Have not seen primary physician so do not know if he has gotten info
- Drs. mention that they will talk to each other
- Certain doctor was better than others but all were pretty good.
- Once getting past initial diagnosis it was great in every way
- Improved by changing primary care. Now it is better, but at the start it was not good
- At the first cancer center I went to it was terrible. At this one it's very good. My two oncologists were in disagreement about my treatment and I got caught in the middle.
- I am very satisfied with the oncologist but I was not satisfied with the surgeon. I had to get a new one.
- Most of the time, went smoothly but Radiology communication is non-existent.
- Oncologists/surgeons were great. My regular primary care physician was useless.
- After diagnosis, I felt like everything went quickly-surgeon, oncologist, receiving treatment. This is my first time so I didn't really know what to expect.

Appendix G: Additional Comments

Summary of Open-Ended Responses to Question 20: "Is there anything else you would like to add?"

Compliments

- No, except the cancer center has been great during these times.
- No, thanks for the chance to provide feedback.
- No. Thank you for your support.
- When I think about this more I may have more suggestions. Right at this time - doing great things
- Thank you for all you people do.
- Thanks!!!
- Thanks for asking us.
- Thanks for survey. I love all my doctors & nurses - they're great.
- Great job
- Keep doing your wonderful job!
- All help is appreciated
- My experience has been great with all agencies involved.
- I have got positive experiences here.
- Everyone here has been a blessing to me
- Chemo nurses ROCK!
- We appreciate the techs and doctors here
- We are very satisfied with this cancer center.
- I have been quite satisfied with my care and feel fortunate with the way things have gone so far.
- I think this cancer center is the best for treatment.
- The cancer center offered excellent care & service throughout to remission.
- Generally I am happy with the staff and services at this cancer center.
- We are very satisfied with the services available at the cancer center.
- All services and staff are the best
- Staff and service at this facility was excellent!!!
- All have been very helpful and attentive.
- Individual attention I received at this cancer center has been superb
- My doctor is excellent and clear about issues we face.
- My physician provided me with wonderful care during my crisis.
- Everyone has been so very kind and helpful
- Everyone at the cancer center has been so friendly and helpful. I'm impressed by the level of care shown.
- The staff here deliver exceptional care and service
- The staff at this cancer center has been superb. I can't compliment them enough.
- The medical treatment was excellent.
- The oncology nurses are wonderful and really do care for the patients
- This cancer center has been very helpful. My doctor has been superb.
- This cancer center is a top run place. Everything is right here and the people are very friendly and helpful
- Have felt fortunate to have such a nice facility and good people to assist me through this time.
- Very satisfied with my treatment center
- This facility is the most compassionate, well organized, and professional health facility we have ever experienced.
- Could not ask for better care.
- Couldn't have been treated any better!
- All the group here are so nice and understanding - wonderful
- Drs. and nurses and most clerical staff at my clinic do an outstanding job.
- We have the best care in the state here.
- The programs are great!
- Treatment is even easier at the new facility
- We are from out of state and are involved in a trial study. Communication, knowledge and coordination was outstanding.
- Sometimes patients just need a knowledgeable, gentle & kind person to talk to and be able to ask questions. Our

- nurse was the kindest person I met throughout my treatment. She is a very valuable asset to the cancer center.
- Bus that brings patients from Deming to Silver City has been very helpful. Without them I couldn't come to treatment
- Thanks for helping me understand the value of life, dealing with cancer for the last 8 months, that I'm cancer free.

Areas for Improvement

Improve Treatment/Clinical Settings

- Make sure dr. & nurses are truly competent
- Less training of new physician, telling him instead of talking to the patient.
- I am not as comfortable with my oncologist as I should be.
- The hospital offers very poor health care
- They should care more about their patients.
- I would like to see a hospital, when you get sick, don't have to go to the ER.
- Get help for people, so they don't have to leave state for treatment.
- We were very disappointed with another cancer center -it was not clean, all the patients shared the same blankets, the chairs were not disinfected, some were broken, my husband was not weighed or vital signs taken before chemo.
- We need to provide psychologists for free to help cancer patients with mental health issues. Someone they can see at the cancer center.

Improve Financial/Insurance Assistance

- It's the financial aspects that are impossible.
- Cancer is a huge financial burden for a single parent without a job.
- Only problem was insurance knowledge, we needed help coordinating. High on my list of extra help: Cancer yoga at High Desert - complimentary.
- Wish insurance covered alternatives.
- People who are sick should NOT have to fight with insurance companies or providers. Cancer care organizations need to take a pro-active approach when patients are diagnosed.
- More Federal support

Provide More Information about Available Services

- Staff at cancer center does not tell the patients about programs in the area that can help them. Money is always donated to the cancer center but the patients don't see it when they need help. Where does the money go?
- Programs could help much more if the patient and caregiver were better informed of their availability. Make resources that are available to the patient immediately known to the patient upon diagnosis.
- Some sort of packet for first timers with cancer might be helpful.

Improve Scheduling

- Scheduling is terrible
- Not satisfied. Had to wait over an hour in dr.'s office before dr. came in.
- A little less waiting for Dr. appointment

Other Comments

- Just keep abreast of medical advice new & old
- We need more caring and compassion in the medical system. It's all money and we need to change that. Money does not have a soul, we do!
- Unable to complete form, but there is a great need for places to live. Casa Esperanza only takes patients with a family member during treatment.
- The cancer patient needs help with everything.
- I pray for a cure for all cancer patients. I do believe the government has a cure.
- Find a cure!

General Comments

- I found this survey very difficult to complete
- Right now I can really think I tried to fill out as much as possible.
- Cancer completely changes you and your family's life - I don't know how to improve this.
- My husband's cancer is well contained and was caught early
- Previous malignant tumor in right lung 1990.
- I had no idea of your existence.
- I wouldn't mind working for this kind of service
- New patient
- Survey given too soon - my first treatments were today - can't answer all questions yet!
- Needs vary depending on stage of treatment. We are fortunate to have medical insurance. We take things one day at a time.
- We didn't use many traditional cancer-related services outside of medical care.
- Suggest local survey on number and types of cancer in this area of the state