A CANCER CARE COMMUNITY NEEDS ASSESSMENT

Diane Korsower M.D.
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EXECUTIVE SUMMARY

Our Cancer Care Program provides services to a very large service area: our primary area, Humboldt County, and our secondary areas, which include Del Norte and Trinity counties in California, and southern Curry County in Oregon. Not everyone within our service area chooses St. Joseph Hospital's program for their cancer care—an average of 43% did so between 2007-2011—but for those who do, the distances involved may be significant.

- Our service area counties are predominantly rural, with beautiful but challenging terrain.
- They are expected to grow in the coming years, but at a rate much slower than California as a whole.
- Our population is older than the average Californian, and aging faster, so we will see an increasing percentage of older citizens in coming years.
- We have a significant number of people living in poverty, again greater than the state as a whole.
- Our population's racial and ethnic picture differs from that of California as well. We have a higher proportion of people who identify as White, American Indian, or "two or more races," but fewer Black, Asian, or Hispanics than California overall. We also have fewer people with foreign-born parents, a higher percentage of Native Americans, and more of our residents speak English as their primary language.
- We have a higher percentage of people covered by publicly-funded insurance.
- Our entire service area has a shortage of health professionals and, crucially, all oncology services for our service area have been located in Eureka.
- Added to this, our service area has a higher incidence rate for all of the common cancer incidence sites compared to the state as a whole. The challenges faced by our patients and clinicians reflect these circumstances.

Community resources for cancer patients exist, but are concentrated in the area around Humboldt Bay. Access to services is very dependent upon patient location and transportation availability, and transportation is, for many patients, a major barrier to timely and comprehensive care and support.
Our Needs Assessment Survey of Patients (2013-14) included respondents from all of our service areas. By design, most respondents were diagnosed within the past five years, to better reflect current experiences with our Cancer Program. About half of our respondents live in the Humboldt Bay area, 18% live south of the Bay, 4% were east of the Bay, and 9% were from Del Norte or Curry Counties. About 60% received some cancer care outside of Humboldt; this includes those who got a second opinion elsewhere but were entirely treated here, those who were treated elsewhere, and those diagnosed elsewhere but treated locally.

In the diagnosis phase of their cancer journey:

- Patients overall reported that once they presented with an initial problem, most were diagnosed during their first visit, although they often had delayed this initial visit due to "other life problems," work responsibilities or lack of insurance.

- After this first visit, diagnostic delays were attributed to the wait for a diagnostic procedure, lack of finances to pay for care, or an (implied) failure to diagnose in a timely fashion on the part of the clinician.

- Most patients said they received results from diagnostic procedures or tests within a week, which is encouraging since this is often a source of anxiety.

- Despite "completely understanding" their diagnosis for the most part, patients also felt the need for more information, and wondered what questions they should be asking. Several respondents suggested a Frequently Asked Questions (FAQ) list to facilitate this.

Patients differed in how much information they wanted concerning their disease and the proposed treatment options. While many sources—written, online, from friends and other people with a similar diagnosis—were helpful to individual patients, having an actual person, i.e., a Navigator, could be helpful in personalizing this process, to provide information sources tailored to a patient's wishes. Some respondents scoured the Internet while others had no computer access or skills. Printed information should be at a level accessible to all (or most) but include references to more technical sources for those wishing that.

Most patients (78%) saw an oncologist within two weeks of diagnosis. Some delays were attributed to being referred out of our area, and some were necessitated by the need to heal after surgery. Patients approached making decisions about treatment in different ways.

- The recommendations by their oncologist were by far the source most used, but patients also ranked "friends and family," local support organizations, Complementary and Alternative Medicine (CAM) and online resources as those they consulted.

- Some felt connecting with other patients who’d had similar diagnoses was very helpful.
• The Humboldt Community Breast Health Project was frequently appreciated by respondents who had used their services.

• Some patients relied entirely on their oncologist's recommendations; others chose to do many hours of online research.

This is another area where a Navigation program could prove valuable, perhaps offering computer search access and guidance for those who want it but lack the means, or facilitating connections between people sharing similar diagnoses, as in the ACS support groups. Overall, however they accessed it, a majority of patients felt comfortable with the amount of information ultimately available to them.

Most patients found supportive sources of information and resources in the community, but this depended on where they lived (outlying areas have fewer resources) and patients wondered if resources existed that they were unaware of. Having a social worker routinely scheduled to see all of our cancer patients seems like a good goal, to review for them available benefit and support resources, but perhaps a Navigator could provide this as well.

The time from oncology consultation to the start of treatment varied, and was impacted by factors like waiting for genetic testing results and scheduling of MRI's.

• Overall, most (69%) of patients began their treatment within two weeks of diagnosis

• Overwhelmingly, patients said they felt involved as much as they wanted to be in decisions about their care and treatment.

• Most said they received a treatment plan summary and information about its potential impact on their life, but their comments suggest that more details, especially about treatment side effects, would be helpful.

• Patients felt clear about which practitioner was 'in charge" of their care (although they didn't all agree on who that was),

• Most who used CAM felt comfortable about sharing this with their oncologist/PMD.

• Most found it easy to contact their doctors when they had important questions, and said that their oncologists were well-prepared with test results and consultation reports during visits.

• Most felt that their privacy was well-preserved during visits, although a few specific circumstances were less so: having blood draws from a port, and during visits for chemotherapy.
Sixty two percent of patients felt they received enough information to enable care at home during treatment and recovery, and most (70%) said they had all the help at home that they needed (but we didn't interview caregivers separately to see how they felt).

Most used at least one source of support services, in particular support groups and counselors. Evergreen Lodge and Angel Flights were appreciated by those who used them.

Again, some respondents commented that they would have used resources if they had known about them at the time, underscoring the need to acquaint patients with what is available.

Patients ranked areas they would have liked more assistance:

1. "Information about available community resources and social services" was the highest-ranked, followed closely by:
   2. "Help understanding diagnostic and treatment options."

Other areas where help was requested include:

3. Keeping track of medical appointments, documents, and medication regimens;
4. Dealing with medical bills and insurance;
5. Information about nutrition and exercise, and of course...
6. Transportation.

We hope our new Cancer Survivorship services will address some of these needs, and that our Patient Navigation program will do so as well.
The Primary Care Providers Survey (2013) addressed primary care physicians, nurse practitioners (NP's), and physician assistants (PA's) in our service area, with practices in community health centers, private offices, and tribal-based offices. Fifty percent of provider participants rated local cancer care as adequate, and 30% rated it excellent.

Providers who gave estimates of their patients' insurance status differed by area, with providers in the McKinleyville/Arcata/Eureka and Fortuna areas more likely to estimate more than 50% of their patients had private insurance coverage or Medicare. Most respondent practitioners estimated that less than 10% of their patients are unauthorized immigrants, but three (one each in Del Norte, Fortuna and Southern Humboldt) estimated 10-50% of their patients were. Our service area counties offer CMSP (County Medical Services Program) coverage only to legal immigrants, so this presents a challenge/barrier to obtaining services for undocumented patients.

Most (70%) respondents feel secure in making up-to-date cancer screening recommendations.

- Still, 40% supported having the Cancer Care Program provide suggested community standards for screening.
- Providers closer to Humboldt Bay report "patient lack of awareness of the importance of screening" and "patient lack of resources" as the most common difficulties they have when recommending cancer screening.
- In outlying areas transportation/accessibility is the foremost challenge providers face in screening their patients for cancer.

Once screening has taken place, what happens to patients when a suspicious finding is uncovered? Are they always followed up? What about after a diagnosis of cancer has been made? Sometimes patients fail to return for results, more often in Fortuna, Del Norte and tribal practices.

- When asked if they tracked these "lost" patients, 43% of respondents answered either "no" or "yes, but inconsistently," again with more of these answers coming from Fortuna, Willow Creek, and Southern Humboldt.

This is a clear area of concern suggesting a need for more investigation, and where a Navigation program might help.
Among practitioners who did track these “lost” patients, we asked what reasons patients gave for not returning,

- “Financial issues” was the most common reason cited
- “Getting a second opinion” was the next most common reason in the area around Humboldt Bay
- "Other life issues have higher immediate priority" and transportation issues were next in importance in Del Norte, Southern Humboldt, Willow Creek and tribal practices,

These results suggest that where medical and other resources are scarce, the choice of a second opinion is a relatively rare one compared to the other challenges patients face.

Within the various practices, some offer more in-house support to cancer patients than others.

- Most commonly this is help with insurance and benefit applications and paperwork; 75% of practitioners in Eureka/Arcata/McKinleyville offer this.
- In Del Norte the available support assists patients in applying for public medical assistance programs.
- Other than finance-related support, the majority of practitioners (58%) offer no other support services for cancer patients in their offices, although tribal practices and community clinics that are part of the Humboldt Open Door system (including their Del Norte Community Health Center) offer counseling services as part of their programs.
A majority (59%) of practitioners report "occasionally" having difficulty referring their patients for treatment locally. Since there are no oncologists in Del Norte County, all of these patients have to be referred out-of-area, making transportation a major challenge there. This was also cited by the other outlying providers. Additional difficulties cited include "lack of enough cancer specialists" and the amount of time it takes to get an appointment, as well as coordinating care.

- Most of the respondents refer at least some of their cancer patients out of our area. The majority refer out less than 10% of the time, although more than half of the Eureka respondents say they refer greater than 10% of their cancer patients out-of-area. "Patient preference" is the most common reason chosen for referring out, followed by "rare cancer type," "more diagnostic modalities available," and availability of clinical trials.

- Most respondents (76%) say their office follows up after referring a cancer patient, to verify the patient has been seen. But not everyone does so: only 50% of respondents in Fortuna, Willow Creek and tribal practices do. This is another point where a Navigation program could assist.

- Most respondents (80%) say they always or usually receive progress reports from local oncologists. This is also so for out-of-area consultants, although this is a bit more spotty. And most respondents said that they remain primarily responsible for non-cancer-related care while their patients are undergoing cancer treatment, which underscores the need for ongoing communication between oncologists and primary care providers.

Providers as a group cited the "adverse effects of treatment" as the most common reason their patients fail to complete their prescribed course. Other problems noted varied in importance by geographic area to some extent:

- Availability of oncology appointments is more of a problem in Del Norte and Fortuna,

- Patient preference for CAM is more common in Southern Humboldt

- Transportation, understandably, more affects patients farther away from Eureka.

- Other problems noted were lack of financial resources and lack of supportive services at home

- Supportive services such as home health were more readily available to practices around Humboldt Bay and in Fortuna, while they were scarce in Del Norte, Willow Creek, Southern Humboldt and tribal areas.

- Homemaker services, where available, were limited to patients with insurance or funds to pay for them.
Most provider respondents reported having difficulties arranging services for their cancer patients, including all practitioners in Del Norte, Willow Creek and tribal practices, as well as two-thirds of respondents from Southern Humboldt. Problem areas include home care, scheduling scans and oncologist visits, paperwork, case management, transportation and hospice care.

Hospice services are very much dependent upon location.

- Eureka, Arcata, McKinleyville and Fortuna practices have hospice available to their patients.
- Del Norte has a program through the Home Health Department of the local hospital.
- Southern Humboldt has a non-Medicare-covered program.

Other areas lack even this. Some practitioner respondents feel that referrals for hospice care are not being made early enough in the final months of a patient's illness.

Sixty-four percent of the respondents have never presented a case to their hospital's Tumor Board, commenting that busy schedules and distance presented barriers. This could perhaps be improved with the use of telecommunication.

When asked for other additions or suggestions to this Provider Community Needs Assessment, practitioner respondents requested:

- More information on ongoing follow-up for their cancer patients once they are no longer regularly seeing their oncologists.
- Improving communications between those performing a cancer screening exam, their patient subjects, and the primary care provider was also mentioned (obtaining results, informing the patient).
- And these primary care practitioners expressed their wish to remain professionally involved in their patients' care throughout the course of their lives.
In summary, this Community Needs Assessment supports the findings of other studies looking at quality issues in health care generally. For patients, communication, trust, caring behavior and comfort, social and spiritual support are crucial values they look for; barriers to quality care include finding reliable health information, lack of coordinated care, lack of psychosocial care, delays in care and billing issues.

All of these are operating here in our cancer service area, but we also face some challenges more specific to us: a geographically large area with cancer care services concentrated in one spot, a shortage both of primary care and oncology specialists, a high rate both of poverty and of cancer incidence, and large parts of our populations with relatively few social support services available to them.

Our survey respondents--both patients and healthcare practitioners--have many suggestions about ways we can improve what we do. Their words and ideas are invaluable contributions to what the Regional Cancer Center Strategic Visioning Task Force of 2007 called for: “...integrated, contemporary cancer services to people living in and around Humboldt County....in a ...facility that will comfort patients, their family and friends, and the caregivers who give so tirelessly of themselves.”*

Readers of this Needs Assessment are urges to continue on to study the comments of the patient and provider respondents.

*A Proposal to Establish a Regional Cancer Center,” The Regional Cancer Center Strategic Visioning Task Force, presented to St. Joseph Health System-Humboldt County, August 2007*
INTRODUCTION

This Community Needs Assessment was created to address a new standard of accreditation set by the Commission on Cancer (CoC) of the American College of Surgeons (ACoS): a Patient Navigation Process, to be phased in by 2015. To quote the CoC: "A patient navigation process, driven by a community needs assessment, is established to address health care disparities and barriers to care for patients."

This Assessment is also another step in the establishment of St Joseph Hospital as a Regional Cancer Center, as outlined in the 2007 Proposal to establish a Regional Cancer Center. It is guided by the principles promoted by the Sisters of St. Joseph of Orange: "Care of the whole person, access to quality health care, consideration for the underserved and marginalized, and stewardship."*

In our case, this is an assessment of many communities, reflecting the large geographic area served by our Cancer Program. We begin with a demographic overview of our service areas, their population characteristics and resources. Then we focus on the "cancer burden" of our area: the current and predicted incidences of cancers, the number of patients and their demographics (age, education, income, insurance status, and language), what their sources of care are and where they are choosing to go for cancer care. Our intent is to assess where we are now in offering cancer care. Our goal is the creation of a Patient Navigation process, but the Assessment itself is not designed to solve the challenges it finds. It can only suggest areas where attention should be paid. Some challenges are part of the "given:" our rural nature, and difficult terrain. Some have much broader implications beyond that of providing cancer care: poverty, shortage of health care practitioners, large areas underserved by community services. But there are many more specific, and more readily addressable, areas where a program such as ours can truly improve the experiences, the quality of care, for everyone: patients, primary care providers, oncologists, and everyone involved with caring for cancer patients. These should be our immediate focus.

Central to this Needs Assessment are the results of two surveys we conducted during 2013-14, one addressing Primary Care Providers in our service area, the other surveying Cancer Patients. Our original Assessment plan included a survey of our cancer care providers -- oncologists, oncology nurses, surgeons, their office staffs, social workers, therapists and such-- and another surveying the other community members who provide services to cancer patients: complementary/alternative medicine (CAM) practitioners, the American Cancer Society, Humboldt Breast Health Project (HBHP), home health workers etc. Their omission here is due to time constraints, but they are clearly major components of our care network. Their contributions to this project have been indispensable, and the patient's comments testify to how crucial a role they play.

* Regional Cancer Center Proposal, p. 1
The content and distribution of these surveys was created with the help of many people in our community: Drs. Theresa Marshall, Bruce Kessler, Jessica Van Arsdale, Mary Meengs, Jerilyn Rubin, Willard Hunter; Nurses Sharon Nelson, Laurinda Koch, Cindi Slater, and Betty Braver; Dan Chandler PhD.; Brenda Elvine-Kreis of HCBHP, staff at the California Center for Rural Policy; staff of the California Cancer Registry; Mignon Dryden, CTR Regional Director, Cancer Registry of Central California Health; Penny Figas, Executive Director, Humboldt-Del Norte Medical Society; Kathy Miller of the Thyroid Cancer Support Group; Peggy Annis of the ACS Cancer Support Group; Pete LaCount, Prostate Cancer Support Group; Kevin Clougherty of SJH.

My deep thanks and indebtedness go to the members of Cancer Care Committee, who have given me their time, wisdom, patience and humor weekly for the past year and a half: Tim Talbert, RN, Jennifer Hooven, Cancer Data Specialist; Janette Garrison BSW; Linda Rasmussen RN MS; Fred Wacker PhD CTR; April Alexander, and the indomitable Ellen Mahoney MD.

And above all, my deepest thanks and admiration to the primary care providers and the patients and caregivers who contributed their experience, their feelings, and their help with this project. I hope I have deserved your confidences.

Diane Korsower M.D.
July 2014
A CANCER CARE COMMUNITY NEEDS ASSESSMENT

In 2007 a local Task Force, specially convened at the request of St. Joseph Health System-Humboldt County, proposed the establishment of a Regional Cancer Center "to ensure the enhancement and modernization of the existing cancer program to best meet the needs of the community." The Task Force envisioned a facility that "will be recognized as a source of coordinated, comprehensive, state-of-the-art cancer care, delivered with respect and compassion." Such a facility is taking shape, but unless patients can readily access the services offered, it will not be able to achieve its goals. This Cancer Care Community Needs Assessment attempts to take stock of what we currently offer to cancer patients, and to learn what barriers patients and their caregivers encounter in cancer screening, diagnosis, treatment, and survival.

We also look at community primary care providers' view of how our cancer care program is working, as they are colleagues integral to the whole spectrum of community cancer care. Our goal: "to identify needs of the population served, potential to improve cancer health care disparities, and gaps in resources," (American College of Surgeons Commission on Cancer 2012 Standards, p.75). We hope this project will help guide us as we establish a Patient Navigation process to address the barriers we discover.

The word “access” comes up repeatedly when talking about cancer care needs. "Access, as defined by the Institute of Medicine (IOM, 1994), is the ‘timely use of personal health services to achieve the best possible health outcomes.’ For certain, access to cancer care is a complex issue. It is more than just ‘getting in the door’ to care; it is about access to care that is timely, appropriate, of high quality, culturally relevant, affordable and coordinated. In addition, access is not limited to cancer treatment services but also includes cancer prevention, screening, and diagnostic services.”*

We also talk about our “community.” So, we begin by looking at who our patients are as a population, their demography, for they come to us from a wide service area made up of many communities.

DEMOGRAPHICS

The general service area for SJH/RMH covers over 7,750 square miles, and three counties: Humboldt, Del Norte and Trinity Counties, with Humboldt being primary. It is made up of many communities, some closely situated, others far-flung and isolated.

Our service area for cancer patients is even larger than that for our hospitals in general, according to 2013 data:*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Humboldt</td>
<td>84.7%</td>
</tr>
<tr>
<td>Del Norte</td>
<td>9.5%</td>
</tr>
<tr>
<td>Trinity</td>
<td>1.0%</td>
</tr>
<tr>
<td>Mendocino</td>
<td>0.2%</td>
</tr>
<tr>
<td>Curry (OR)</td>
<td>3.9%</td>
</tr>
<tr>
<td>Other</td>
<td>0.7%</td>
</tr>
</tbody>
</table>

* Kevin Clougherty, Area Director of Financial Operations & Business Development at St. Joseph Health - Humboldt)
It seems some of our patients come from even further than we supposed, from the Oregon County just to our north. This enlarges our cancer service area to 9,377 square miles. We will need to take this into our planning for seamless patient care.
There are 7 other acute-care hospitals in this service area: Curry General Hospital in Gold Beach, Oregon (22 beds); Sutter Coast Hospital (49 beds), in Del Norte County; Trinity Hospital, in Weaverville (47 beds) in Trinity County. In Humboldt County we have Mad River Community Hospital (68 beds), Jerold Phelps Community Hospital in Garberville (16 beds) and Redwood Memorial hospital in Fortuna, part of the St Joseph system (25 beds). In comparison, St Joseph Hospital has 138 beds and is the sole provider of radiation oncology in our service area. All the medical oncologists for our area were also located in Eureka during the time of this Assessment.

<table>
<thead>
<tr>
<th>County</th>
<th>Hospital</th>
<th>Beds</th>
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<tbody>
<tr>
<td>Humboldt</td>
<td>Mad River Community Hospital, Arcata</td>
<td>68</td>
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<tr>
<td></td>
<td>Jerold Phelps Community Hospital, Garberville</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Redwood Memorial Hospital, Fortuna</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>St. Joseph Hospital, Eureka</td>
<td>138</td>
</tr>
<tr>
<td>Del Norte</td>
<td>Sutter Coast Hospital, Crescent City</td>
<td>49</td>
</tr>
<tr>
<td>Trinity</td>
<td>Trinity Hospital, Weaverville</td>
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</tr>
<tr>
<td>Curry (OR)</td>
<td>Curry General Hospital, Gold Beach</td>
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</table>
Cancer patients in our cancer service area face all the common challenges this diagnosis brings, but also may encounter issues more specific to our area.

**POPULATION**

Our counties are rural, or "non-metropolitan," to use the OMB (US Office of Management and Budget) definition. These areas are densely forested, mountainous inland, with most of the population along the coast. In Humboldt County, approximately half of the population (134,584 total in 2012) lives in incorporated communities, and 59% live in the area around Humboldt Bay (this includes Arcata, Ferndale, Fortuna, Eureka and McKinleyville). There are roughly 38 people per square mile. In Del Norte County (pop 28,248 in 2012) the population is 66% urban, centered in Crescent City; the population density is 28.4 per square mile. Trinity County (2012 pop 13,506) is considered all rural, with a population density of 4 people per square mile. Curry County, Oregon (2012 pop 22,274) has a population density of 13.7.*

The population of Humboldt County is expected to grow in the coming years, but at a rate much slower than the state average. Humboldt is expected to reach a population of 143,107 by 2025, a 6.3% increase. Del Norte will increase by 6.3%, to 30,358 by 2025. Trinity is projected to grow by 9.9% and Curry County OR by 3.1%. By comparison, California as a whole is projected to grow 13.9% by 2025, to 42,451,760.

<table>
<thead>
<tr>
<th>County</th>
<th>% Change</th>
<th>2010</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
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</thead>
<tbody>
<tr>
<td>Humboldt</td>
<td>6.3%</td>
<td>134,663</td>
<td>135,681</td>
<td>139,132</td>
<td>143,107</td>
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<tr>
<td>Del Norte</td>
<td>6.3%</td>
<td>28,544</td>
<td>28,678</td>
<td>29,635</td>
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<td>Trinity</td>
<td>9.9%</td>
<td>13,713</td>
<td>13,524</td>
<td>14,352</td>
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<td>Curry (OR)*</td>
<td>3.1%</td>
<td>22,364</td>
<td>22,112</td>
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<tr>
<td>California</td>
<td>13.9%</td>
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<td>42,451,760</td>
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Oregon department of Health Services
Other data from California Dept. of Finance, Report P-1, Jan 2013

(In passing, I note that this projected growth rate for our service area shows slowing from that projected in the 2007 Regional Cancer Center proposal, which estimated a 9% increase in our service area population [excluding Curry County], from 2000 to 2019.)

* State & County QuickFacts, US Census Bureau.
AGE

Our population is older than the average Californian, and growing older yet. In 2012, Humboldt had 14.4% of its population aged 65 and older, compared to California as a whole at 12.1%. Del Norte had 14.6%, Trinity County had 22%, and Curry County had 30%.

By 2020, California as a whole is projected to have 14.7% of its population 65 and over. For Humboldt County the projection is 19.9%, for Del Norte, 18.4%, for Trinity 28.3% and for Curry County a whopping 35%.

Sources: Oregon Department of Human Services, "Your Community In focus: Curry County, [http://www.oregon.gov/dhs/spwpd/ltc/ltc30/curry.pdf](http://www.oregon.gov/dhs/spwpd/ltc/ltc30/curry.pdf)
California dept. of Finance Jan 2013 P-1 State & county population projections by age
Another way to see this is to look at median age. California's median age in 2010 was 35 years, while Humboldt's was 37, Del Norte's median age was 39, and Trinity County's median was 49. California's median age is expected to rise to 38.9 by 2030, and Humboldt's to rise to 40.0 to 44.9, Del Norte to 45-49.9, Trinity to 50-58.4.

Thus, while our area is expected to grow less rapidly than the rest of the state, we will see an increasing percentage of older citizens. And since most cancers increase in incidence by age, this will likely result in an overall increase in the rate of cancer diagnosis.
POVERTY

Our counties have a significant number of people living in poverty. For 2008-2012, Humboldt had 19.7% of people living below poverty level, Del Norte had 21.5%, Trinity had 17.7%, and Curry County had 13.7%, while for California as a whole the rate was 15.3%

Percentage of people living below the poverty level 2008-2012

<table>
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<th>Social Security</th>
<th>SSI</th>
<th>Public Asst.</th>
<th>Food Stamps</th>
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<tbody>
<tr>
<td>Humboldt</td>
<td>28%</td>
<td>7.9%</td>
<td>3.9%</td>
<td>8.2%</td>
</tr>
<tr>
<td>Del Norte</td>
<td>39%</td>
<td>10.8%</td>
<td>8.5%</td>
<td>13.6%</td>
</tr>
<tr>
<td>Trinity</td>
<td>44%</td>
<td>9.2%</td>
<td>2.7%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Curry (OR)</td>
<td>49%</td>
<td>6.2%</td>
<td>4.7%</td>
<td>16.5%</td>
</tr>
<tr>
<td>California</td>
<td>25%</td>
<td>5.5%</td>
<td>3.8%</td>
<td>7.2%</td>
</tr>
</tbody>
</table>

This increased poverty is also reflected in the median household incomes. For Humboldt in 2012 this was $40,682; for Del Norte it was $37,305; for Trinity it was $35,162; and for Curry County OR it was $34,854. Seen in comparison to the median income of Californians overall, at $68,322, it reveals a significant disparity.

We can also glimpse the economic situation of our local population by comparing the proportion of households receiving Social Security, Supplemental Security Income, cash public assistance or Food Stamps.

Source: Selected Economic Characteristics, 2012 American Community Survey 3 year estimates 2008-2012 DP03
RACE & ETHNICITY

Our population's racial and ethnic picture differs from the state as a whole as well. We have a higher proportion of people who identify as White, American Indian, or "2 or more races," but fewer Black, Asian, or Hispanics than California overall. We also have fewer people with foreign-born parents.

Within the Redwood Coast region, Latinos are the fastest-growing ethnic group, but are still much more of a minority than in California as a whole:

People identifying as Hispanic or Latino (2012):

<table>
<thead>
<tr>
<th>Humboldt</th>
<th>Del Norte</th>
<th>Trinity</th>
<th>Curry (OR)</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.3%</td>
<td>18.8%</td>
<td>7.0%</td>
<td>6.5%</td>
<td>38.2%</td>
</tr>
</tbody>
</table>


However, we have a higher percentage of people identifying as Native American:

People identifying as Native American (2012):

<table>
<thead>
<tr>
<th>Humboldt</th>
<th>Del Norte</th>
<th>Trinity</th>
<th>Curry (OR)</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.2%</td>
<td>8.8%</td>
<td>4.9%</td>
<td>2.2%</td>
<td>1.7%</td>
</tr>
</tbody>
</table>

Compared to California overall, we have fewer people whose language spoken at home is other than English: Humboldt 9.3%, Del Norte 15.8%, Trinity 6.7%, and Curry County, OR 5.1%, compared to California overall (43.5%). While the predominance of English-speakers here makes health communications simpler, those whose first language is other than English may experience more difficulties in accessing health care and related information than in other areas of the state.

Language other than English spoken at home

<table>
<thead>
<tr>
<th>Humboldt</th>
<th>Del Norte</th>
<th>Trinity</th>
<th>Curry (OR)</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.3%</td>
<td>15.8%</td>
<td>6.7%</td>
<td>5.1%</td>
<td>43.5%</td>
</tr>
</tbody>
</table>

Source: US Census QuickFacts for 2008-2012
EDUCATION

Educationally, our four-county service area is less homogeneous. We do have a higher rate of high school graduates, but fewer have graduated college compared to the state of California.

Of people over 25, 90% of Humboldt’s population are high school graduates, and 26% have a college degree or higher. This compares with Del Norte (79% and 14%, respectively) and Trinity (91% and 20%) counties, with Curry County OR (90.8% and 20.4%) and with California as a whole (81% and 30%).

**Education Demographics Over Age 25**

- **Humboldt**:
  - High School: 90%
  - College or Higher: 26%

- **Del Norte**:
  - High School: 79%
  - College or Higher: 14%

- **Trinity**:
  - High School: 91%
  - College or Higher: 20%

- **Curry (OR)**:
  - High School: 90.8%
  - College or Higher: 20.4%

- **California**:
  - High School: 81%
  - College or Higher: 30%
SPECIFIC HEALTH CARE DEMOGRAPHICS

INSURANCE STATUS

Looking specifically at access to health care, our population has had a higher rate of public health insurance coverage.

When we consider at the “civilian non-institutionalized population” between ages 18 and 64, all four counties have had a higher-than-California-overall percentage of people covered only by public insurance. Taken as a whole we don't have a higher percentage of uninsured people aged 18-64:

Civilian Non-Institutionalized Population (18-64) Public Insurance vs. Uninsured

Source: American Community Survey 2008-2012 C27010, SAHIE estimates from US Census 2012

(These figures will undoubtedly change with the implementation of the Affordable Care Act.)
HEALTH CARE PROVIDER SCARCITY

All four counties are designated Health Professions Shortage areas, meaning that the ratio of population to FTE (full-time-equivalent) primary care providers is at least 3500:1.

All oncology specialists (radiation, medical) in our four county service area have been located in Eureka through 2013. We have averaged 5 oncology specialists (2 radiation oncologists, 3 medical oncologists) in recent years, which is already below the projected "demand" figures used in our 2007 Regional Cancer Care Proposal. The projected demographic changes--an increasingly aging population--in our area will increase our need for oncologists and surgeons (and for primary care providers.)

TRANSPORTATION TO HEALTH CARE SERVICES

The overall low population density, poverty, and geographic factors in our counties result in transportation challenges for many residents needing access to health care services. As the California Center for Rural Policy (CCRP) stated in their 2009 study, "Limited or no public transportation, needing to travel far distances for specialty care, inhospitable terrain and weather have all been identified as barriers to accessing health care among rural populations."*

Transportation is a particular challenge for the poor, the non-white population, and those living in an area with low population density. Twenty-five percent of non-white respondents in CCRP's 2006 study (Rural Health Information Survey) of our counties reported transportation as a problem in meeting health care needs, compared to 15% of whites. This is made worse in the case of cancer care, where specialized services are only available in Eureka. For the 40% of Humboldt's population who don't live close to the Bay, and for all the people in Del Norte, Trinity and Curry counties, transportation can prove a major barrier to accessing care.

Transportation is even more challenging for those who require cancer care beyond what is available in Eureka, as discussed below.

*"Transportation Disparities Impacting Health Needs in the Redwood Coast Region," California Center for Rural Policy (CCRP) Research Brief 4, July 2009, p. 3
WHAT IS OUR "CANCER BURDEN"?

Our (approximate) service area has a higher cancer incidence rate than California as a whole for all of the five most incident cancer sites:

### Incidence Rates* for 5 most incident cancer sites in California and Humboldt/Del Norte/Trinity Counties, 2007-2011

<table>
<thead>
<tr>
<th>CANCER SITE</th>
<th>CALIFORNIA</th>
<th>HUMBOLDT/DEL NORTE/TRINITY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Site Rate*</td>
<td>Case Count</td>
</tr>
<tr>
<td>COLON &amp; RECTUM</td>
<td>40.2</td>
<td>74,247</td>
</tr>
<tr>
<td>LUNG &amp; BRONCHUS</td>
<td>46.6</td>
<td>86,177</td>
</tr>
<tr>
<td>SKIN</td>
<td>22.5</td>
<td>41,606</td>
</tr>
<tr>
<td>BREAST</td>
<td>64.9</td>
<td>119,946</td>
</tr>
<tr>
<td>PROSTATE</td>
<td>61.1</td>
<td>112,934</td>
</tr>
</tbody>
</table>

*Incidence rates express the number of cancers per 100,000 population, age-adjusted to the 2000 population. 
Source: California Cancer Registry
How many people do these figures indicate? The number of individuals in most of our service area (excluding Curry County OR) who were diagnosed with an invasive cancer between 2007 and 2011 is shown in the following table. This is an approximation since the California Cancer Registry combines the data from Del Norte and Trinity counties. Some residents of Trinity County (total population 13,526) do come to Eureka for care, but not all. However, we also draw some residents of Curry county (total population 22,248), which is not counted in these figures.

**Case Counts of the Most Common Cancers in the Service Area 2007-2011**
(from California Cancer Registry and NCDB)

<table>
<thead>
<tr>
<th>CANCER SITE</th>
<th>HUMBOLDT #cases</th>
<th>%total</th>
<th>DEL NORTE #cases</th>
<th>%total</th>
<th>TOTAL #cases</th>
<th>%total</th>
<th>PTs dx @ SJH #cases</th>
<th>%total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung/Bronchus</td>
<td>414</td>
<td>12%</td>
<td>229</td>
<td>18%</td>
<td>643</td>
<td>14%</td>
<td>231</td>
<td>37%</td>
</tr>
<tr>
<td>Prostate</td>
<td>602</td>
<td>17%</td>
<td>184</td>
<td>15%</td>
<td>786</td>
<td>17%</td>
<td>229</td>
<td>29%</td>
</tr>
<tr>
<td>Colon &amp; Rectum</td>
<td>346</td>
<td>10%</td>
<td>84</td>
<td>7%</td>
<td>429</td>
<td>9%</td>
<td>159</td>
<td>37%</td>
</tr>
<tr>
<td>Female Breast</td>
<td>458</td>
<td>13%</td>
<td>172</td>
<td>14%</td>
<td>630</td>
<td>13%</td>
<td>362</td>
<td>57%</td>
</tr>
<tr>
<td>Non-Hodgkins Lymphoma</td>
<td>158</td>
<td>5%</td>
<td>55</td>
<td>4%</td>
<td>213</td>
<td>5%</td>
<td>74</td>
<td>35%</td>
</tr>
<tr>
<td>Brain/Nervous System</td>
<td>51</td>
<td>2%</td>
<td>17</td>
<td>1%</td>
<td>68</td>
<td>1%</td>
<td>30</td>
<td>44%</td>
</tr>
<tr>
<td>Urinary/Bladder</td>
<td>180</td>
<td>5%</td>
<td>58</td>
<td>5%</td>
<td>238</td>
<td>5%</td>
<td>153</td>
<td>64%</td>
</tr>
<tr>
<td>All Others</td>
<td>1,250</td>
<td>36%</td>
<td>444</td>
<td>36%</td>
<td>1,694</td>
<td>36%</td>
<td>784</td>
<td>46%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>3,4959</td>
<td>100%</td>
<td>1,243</td>
<td>100%</td>
<td>4,702</td>
<td>100%</td>
<td>2,022</td>
<td>43%</td>
</tr>
</tbody>
</table>
CANCER PATIENT DEMOGRAPHICS

More specifically, who are "our" cancer patients? Using the most recent (2011) available data from the National Cancer Data Base (NCDB), for all cancer patients seen at SJS, we can get an idea.

- 88% are over age 50, 68% are over age 60. (Graph I)
- 52% are male, 48% are female
- They are mostly white (94%) (Graph II)
- Most of them have some form of government insurance (Graph III)
- Most have a high school education (Graph IV)
- They are mostly low income (Graph V)
- Those treated at St. Joseph’s travel considerable distances to get there compared to other California community cancer programs (Graph VI, VII)

Graph I

Age Demographics for all Cancer Patients at SJH, 2011
Graph II

Race Demographics for all Cancer Patients at SJH, 2011

Graph III

Insurance Demographics for all Cancer Patients at SJH, 2011
Graph IV
Education Demographics (% without High School degree) for all Cancer Patients at SHJ, 2011

Graph V
Income Demographics for all Cancer Patients at SJH, 2011
(Parenthetically, for Redwood Memorial, of a total of 17 cancer patients in 2011, 88% traveled 25 miles or less.)
WHAT ARE OUR COMMUNITY RESOURCES?

This list is admittedly incomplete. We haven’t included the individual counselors, health practitioners, church-based groups, or general community assistance programs, but it does contain most of the specifically cancer-related resources.

HOME HEALTH AND SUPPORT SERVICES

- St. Joseph Home Care available to Eureka and Fortuna
- Mad River Hospital Home Care available to Arcata, Eureka, McKinleyville, Blue Lake, and Orick
- Sutter Coast Home Care in Crescent City
- Assisted Living Services, Inc., available to Eureka & “surrounding areas of Humboldt County”
- Humboldt Caregivers, serves Humboldt and Del Norte Counties
- Visiting Angels, serves Humboldt County coastal areas from Trinidad to Scotia
- In Home Support Services (IHSS)—patients must be low-income/receiving Medi-Cal; a program managed in Humboldt County—by the Dept. of Health & Human Services,
- Caregiver Services Program, Area 1 Agency on Aging (Humboldt and Del Norte Counties)
- Community Resource Center, serves Eureka
- Humboldt Senior Resource Center, serves Humboldt County from Scotia to Trinidad, and inland to Blue Lake and Carlotta
- Del Norte Senior Center, serves Crescent City
- Crescent City Lunch Site (home delivered meals)
- Healy Senior Center of Southern Humboldt, centered in Redway
- American Cancer Society office in Eureka (no other ACS office in our service area; this list comes from the National ACS)
- Look Good, Feel Better program
(Home health and support services cont’d...)

- Reach to Recovery (transportation to cancer treatment by volunteers)
- Road to Recovery
- Personal care items (wigs, turbans)
- Support groups
- See's Community Fund
- Public transportation vouchers, and special door-to-door van service for disabled within service area
- Volunteer Center of the Redwoods (50 years or older or physically disabled; service area includes Scotia North, Ferndale East, Carlotta West and Loleta South.
- Guest Room/Patient Housing: short-term overnight accommodations for cancer patients who must travel >50 miles or 90 minutes to out-patient treatment center.
- National ACS also offers toll-free 24/7 hotlines staffed by Cancer Education specialists to answer questions and provide referrals
- Dial-A-Ride (for Eureka/Arcata/McKinleyville)
- Evergreen Lodge
- Kris Kelly Health Information Center, located in Evergreen Lodge
- Angel Fund of the Union Labor Health Foundation
- Humboldt Senior Resource Center
- Adult Day Health Services
- PACE (Programs of All-Inclusive Care for the Elderly)
- Humboldt County Breast Health Project (Arcata & Fortuna)
• Arcata and Fortuna Breast Cancer Support Groups

(*Home health and support services cont’d...*)

• Amazon Writers (Arcata)
• Advanced Disease Support Group (Arcata)
• Gynecologic Cancer Support Group (Arcata)

Other cancer support groups:

• Prostate Cancer Support Group (meets in Eureka)
• Thyroid Cancer Support Group (meets in Eureka)
• Cancer Support Group (General) (meets in Eureka)
• Hospice of Humboldt, services within a 50 mile radius of Eureka
• Heart of the Redwoods Community Hospice Garberville (southern Humboldt)
• Advanced Illness Management (AIM) program of the Sutter Coast Hospital's Home Health department (Crescent City)
• Coastal Home Health & Hospice (Gold Beach & Brookings, OR)
• Curry County Home Health Hospice (Gold Beach, OR)
• Palliative care program, St Joseph Hospital, available "within the service area of SJH"
The next sections of this Community Needs Assessment are the results of surveys conducted in 2013-14. Their goal was to assess where we are now in our provision of cancer care services, as seen by our patients and their caregivers, and then by our local primary care providers. Our goal was to help guide the creation of our Cancer Patient Navigation program by taking a "snapshot" of how these groups experience cancer care services in our area. The Needs Assessment itself is not designed to solve problems, but to elucidate them. Each of these sections will describe the processes used and summarize the results. A summary of the results and conclusions follows. Valuable insights are also to be found in the comments contributed by individual respondents, included in the body of the reports. The survey questions themselves can be found in the Appendix.
SURVEY OF CANCER PATIENTS AND THEIR CAREGIVERS

PURPOSE AND METHODS:

At the center of this Community Needs Assessment are the patients—current, past, and future—and their caregivers. We sought them out through ACS support groups, through the Humboldt Breast Health Project, from the chemotherapy infusion suites at St. Joseph Hospital and Eureka Internal Medicine, and at Evergreen Lodge. The staff at all of these sites was crucially instrumental and generous with their time, helping to suggest and introduce their patients and otherwise facilitate the process. Other patient contributors came from our own friends, and friends of our friends. Patients were surveyed individually while receiving chemo infusions, at their homes, at Evergreen Lodge or via the Internet at their convenience. Often their caregivers were present and contributed, so the results reflect their input as well. All participants were assured of the confidentiality of their responses, and that they would remain anonymous.

Since the questions were designed to inform us as we create our Patient Navigation Program, we sought to discover barriers patients and caregivers experienced in the course of their diagnosis, treatment, and thereafter. Some sources for questions came from published surveys, some were suggested by local healthcare professionals, and some were our own. Sources are listed in our References section and the survey questions, are included in the Appendix.

The comments of the participants are particularly enlightening, and we've included many of them for their valuable insights into the patient experience.
PATIENT RESPONDER DEMOGRAPHICS

All told, 55 patient respondents completed the survey. Their average age was 60, their median age was 64. Seventy-four percent were female, twenty-six percent male, a reflection perhaps of the enthusiastic response from clients of the Humboldt Breast Health Project.

We made an effort to solicit input from all parts of our service area, since distance plays such a major role in accessing and receiving care in our area.

- 51% of our respondents were from the Humboldt Bay area (Eureka, Arcata, Bayside).
- 13% were from the area of Humboldt county north of the Bay (McKinleyville, Trinidad, Westhaven)
- 11% were from "south central" Humboldt (Fortuna, Loleta, Hydesville)
- 7% were from southern Humboldt (Rio Dell, Myers Flat, Garberville, and Redway)
- 4% were from eastern Humboldt (Weitchpec, Bridgeville)
- 9% were from Del Norte county or Oregon
• Most (63%) live with a spouse or life partner, or with other family members or friends (24%). Five (10%) live independently, and 2 (4%) have no fixed place to live.

• Our sample is an educated one, with 85% reporting at least some college study. Thirty-nine percent completed college, and 15% have graduate degrees. (In US Census data, Humboldt reports 26% of the adult population have a bachelor's degree or higher; Del Norte is at 14%.)

• English is the first language for all but one of my respondents. This again contrasts with US Census data noted in the Demographics section. Thus, non-native-English-speakers are underrepresented here.

❖ The patient respondents' cancer sites/types varied
54 of them identified a site, with 6 reporting more than one primary:

<table>
<thead>
<tr>
<th>CANCER SITE</th>
<th># OF CASES</th>
<th>% OF RESPONDENTS WITH THIS SITE</th>
<th>PERCENTAGE OF TOTAL CANCERS IN HUMBOLDT*</th>
</tr>
</thead>
<tbody>
<tr>
<td>BREAST</td>
<td>22</td>
<td>41%</td>
<td>13.7%</td>
</tr>
<tr>
<td>NON-HODGKINS LYMPHOMA</td>
<td>9</td>
<td>17%</td>
<td>4%</td>
</tr>
<tr>
<td>PROSTATE</td>
<td></td>
<td>9%</td>
<td>17%</td>
</tr>
<tr>
<td>OVARY</td>
<td>5</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>COLON</td>
<td>2</td>
<td>4%</td>
<td>10%</td>
</tr>
<tr>
<td>LUNG</td>
<td>4</td>
<td>7%</td>
<td>11%</td>
</tr>
<tr>
<td>MELANOMA</td>
<td>2</td>
<td>4%</td>
<td>5.5%</td>
</tr>
<tr>
<td>BRAIN/NERVOUS SYSTEM</td>
<td>2</td>
<td>4%</td>
<td></td>
</tr>
</tbody>
</table>

*Source: California Cancer Registry

Other cancer sites as reported by respondents included single cases of: primary peritoneal, endometrial, sarcoma, multiple myeloma, neuroendocrine carcinoma, metastatic squamous cell, “tongue”, “gastro-intestinal,” Hodgkins lymphoma, HPV+ squamous cell of the oropharynx.
Since our aim in this survey was to capture the current experience of cancer patients, the data reflects this in our patient sources. We wanted to hear from people with relatively recent experience with cancer care here, and so solicited input from patients currently in treatment, and asked the HCBHP to find participants diagnosed within the past five years. We also visited ACS cancer support groups to seek participants; some of these folks had more distant diagnoses. A total of 52 participants recorded diagnosis dates, and 73% were diagnosed in the past five years, including 12 (23%) in the past year.
PATIENT ACCESS TO CARE

In our widespread service area, access to health care can be challenging for many different reasons: distance to care providers, available transportation, availability of care providers, and insurance coverage or its lack. This is even more challenging, and more crucial, for cancer care, since the cancer specialists have all been located in Eureka.

Most of our respondents (67%) live within ten miles of their primary care provider (PCP); another 24% live 10 to 20 miles away, and one lives 50 miles away. Almost everyone gets to their PCP by car, and most (58%) report they drive themselves to appointments.

Specifically regarding cancer care, for those receiving care out of our area, the distances can be considerable: a total of 13 respondents traveled between 200 and 400 miles (each way).

Overall, 37 (70%) indicated having at least some oncology appointments further than 10 miles from home, but 39 (74%) traveled less than 100 miles for at least some of their appointments. A total of 5429 "miles to your oncologist" were reported from 52 respondents, with 4 of them reporting 2 different cancer care sites, reflecting that they consulted more than one oncologist. Of the total respondents reporting their total distances traveled, this averages to 104 miles per patient-oncologist trip, with a range from 3 blocks to 400 miles.

The patients' means of transportation varied, reflecting both the distances involved and their ability to drive independently. Eighteen (34%) drove themselves, another 19 (36%) were driven by family or friends, 2 took a bus and 3 used Angel Flights.

COMMENTS:

- “(I travel to) Eureka 80 miles. My wife drives me because I have to take part of my medications before leaving home.”

- “My oncologist is in Eureka, and I am currently staying in Weitchpec with my family and my roommate. Weitchpec is about two hours from Eureka, and I want to find someplace in Eureka to live while I’m in treatment here.”

- “I see people at UCSF...375 miles at least twice a year and I drive, alone or with my partner.”

- “Local medical oncologist in Eureka, 23 miles. Depending on the chemo I’m getting, sometimes I drive myself; sometimes I get rides from friends. Gynecological oncologist at UCSF, 300 miles. Drive myself, Greyhound bus, or Angel Flight; stay with friend in Sausalito.”

- “(I travel) 280 miles. My husband drives me or I use Angel Flights.”
(comments cont’d…)

- “Bridgeville is about 45 miles from Eureka, where my oncologist is. During my treatment I have been living with a friend in Eureka, so I'm about 3 miles from my oncologist. My friend drives me.”

- “All of my providers are in Eureka, 20+ miles from my home. In the beginning of my cancer journey I traveled to Stanford-I don't know how many miles away-it's far! My parents drove my husband and me down because neither of us has experience driving in big cities.”

- “(I travel) about 80 miles. At first I took a bus, but now some people from church give me a ride.”

Most respondents (83%) aren’t receiving any benefits as a result of their cancer diagnosis, but some at least would like some help with this area:

**COMMENTS:**

- “I would have liked social services to have checked if I could be eligible State Disability which is less than my paycheck used to be.”

- “I was turned down for SSDI and disability retirement from STRS a year ago. I've been able to work ten days since.”

- “Currently receiving State Disability Insurance and due to expire at the end of February. Unknown if I will need to apply for SSI disability.”

- “I am a T6 spinal cord injury individual and receive disability because of this issue.”
About 60% of respondents said they received some cancer care outside of Humboldt. Reviewing their individual entries provides more detail:

- Those treated only within Humboldt 21 (39%)
- Those consulting out of area (second opinion) but treated here only: 8 (15%)
- Those leaving area for treatment not available here (GYN, brain, etc.): 13 (24%)
- Those leaving area because of dissatisfaction with local options: 2 (4%)
- Those initially diagnosed out-of-area, treated there then transferred care here: 6 (11%)
- Those participating in a clinical trial: 1 (2%)
The patient’s comments reveal some of their experiences when leaving our area for care.

**COMMENTS:**

- “I went to Stanford for a second opinion at the urging of friends. I felt full trust in Dr. X (ENT) and Stanford agreed with the local recommendations and said Eureka is fully equipped to handle it. I was more afraid of the treatment than I was of the cancer, and actually I think I got better care here because I don’t think Stanford would have settled for less than 7000 rads but Dr. Y (rad onc), at my request, did so.”

- “I was first seen in San Luis Obispo, then transferred to a hospital in Santa Barbara for surgery. My father wanted me to come back to Humboldt to see Dr. X (oncologist), who had taken good care of him when he had cancer, and where my family could help me. Dr. X did refer me down for a second opinion to UCSF as well, but my treatment is happening here.”

- “I was referred to Stanford and have been there four times, most recently for bone marrow transplant.”

- “I went to Stanford as recommended by our local Tumor Board. My treatment has been local, here in Eureka.”

- “Besides the chiropractor in Brookings, we got a second opinion from an oncologist at OHSU in Oregon. Our oncologist here seemed a little upset with us because they wanted us to go to Stanford. Our daughter lives near OHSU, and we didn't understand that going to Stanford didn't mean that we had to be treated at Stanford, so we went to where our daughter could help us if we had treatment there.”

- “I began my chemo here but after 4 rounds my oncologist recommended I go to UCSF for intraperitoneal treatment, which isn't available here.”

- “My oncologist and radiation oncologist are in San Luis Obispo County. I no longer see the oncologist and Dr. X (surgeon) is my primary cancer doctor now.”
Regarding health insurance coverage at the time of first diagnosis:

- 62% (33 of 53) had private insurance
- 32% (17) had Medicare
- 28% (15) had a supplemental policy
- 9% (5) had MediCal or other public policy coverage
- 4% (2) had no insurance

(This totals more than 100% because some patients had more than one form of insurance.)

Respondents with multiple forms of insurance:

- 23% (12) respondents had Medicare plus supplemental coverage
- 4% (2) had private insurance plus supplemental
- 6% (3) had Medicare plus private insurance
- 2% (1) had MediCare and MediCal
- 2% (1) had MediCare, private and supplemental coverage

(The results reflect the ages of the respondents, since eligibility for MediCare begins at age 65.)
COMMENTS:

- “I also had Veteran’s health coverage, but I think care from the VA is horrible. I’m so thankful I had MediCal.”

- “I didn’t have any insurance at first, and we paid the surgeon ourselves, but his office helped arrange for me to get MediCal. Now I have Medicare too.”

- “I soon found PCIP. Pre-existing Condition Insurance which carried me through until they put me on Medicare.”

- “I’m taking a medical leave of absence from my job at Walmart. I keep my insurance from work, but have to pay for it myself.”

- “(I have) Veterans Benefits SSI for my back problems.”
THE CANCER DIAGNOSIS EXPERIENCE

What led respondents to their diagnosis? Just about half (52%) of our surveyed patients sought care within a month of first experiencing symptoms that proved to be due to malignancy. Five (12%) took more than 6 months. Looking at the 27 comments to this question, 16 patients experienced symptoms attributable to their cancer before seeking care, and 8 had cancers found incidentally by screening or routine care. Their comments also illustrate some of the barriers to accessing care.

COMMENTS:

- “I didn’t realize I had symptoms. I was tired but I thought that was because of stress and of getting old. I had some routine lab work done before my yearly physical and my doctor called me at home to say I should go to the ER right away because my sodium level was very low. I was admitted to the hospital then, had a chest X-ray and they saw a mass.”

- “I had 3 blood clots in my leg, and they did a chest X-ray and found it.”

- “I started having trouble eating in 1998 when I was in military boot camp. I also had an abnormal Pap smear then, but they didn’t do anything about that, and I was told there wasn’t anything wrong that they could find. Then I was on a military ship in Japan and I figured I was stressed out or something. I did see a doctor at the VA at least 5 times between 2012 and 2013, but all she did was tell me to take Prilosec. I wasn’t diagnosed until I went to an ER.”

- “It was hard because I didn’t have insurance. I did have access to United Indian Health because I am married to a Native American, but any outside or special care was not covered. If I had insurance I probably would have done something a lot sooner and they probably would have got it all the first time and saved my leg.”

- “I have a (family) history of breast cancer. I had asked my primary care giver if I needed an early mammogram at age 38 and she said no. One year later I was diagnosed with stage 3 breast cancer.”

- “3-6 months after initial suspicion that something was wrong. Another 9 months after I was given ok from my doctor before I went in again and was referred to cancer specialist.”

- “I was diagnosed at my annual exam, although in retrospect I had been having some mild symptoms of ovarian cancer but I didn’t realize it at the time.”
For those who delayed seeking care, we asked why. Thirty-eight respondents replied: 17 of them reported a delay, 21 specified there was no delay.

For those reporting delay, we used a 1-4 scale to rate how important a given factor was (with 4 being most important).

“Other life problems were more important” scored the highest as a reason for delay. Next highest was “work responsibilities”, followed by (tied) “financial reasons/lack of insurance/high deductible/couldn’t afford” and “fear”. But for some respondents, lack of a primary care provider and “lack of trust in doctors” had rankings as most important, and “caregiver responsibilities” were important for two.

Six of the commenters suggest that the delay in diagnosis was due to their providers' actions (or inactions), which is 16% (6 of 38) of those who gave a response.

**AVG RATING OF REASONS FOR DELAY IN CARE**

- Work: 3
- Other life problems: 3
- Financial: 2.76
- Afraid: 2.5
- Childcare/caregiver: 2.33
- Don't trust docs: 2.33
- No primary care: 2.25
- Transport: 1
 COMMENTS:

• “I felt some breast changes and had a doctor do an exam. She didn't find anything unusual and said all seemed fine. I asked if I needed an early mammogram due to a strong family history of breast cancer. She told me I did not. I returned 9 months later as the area of concern was changing/growing.”

• “I had to put on a program out of the area, one that I do every year. I put off going to see my doctor about the lump until I got back.”

• “I didn't delay going to the doctor. The delay was in diagnosing the cancer.”

• “I didn't delay. Because the military doctors told me there wasn't anything they could find on their exams, I thought it was stress, and I was on a ship for most of the time. Then I saw the VA doctor but she didn't do anything.”

• “It went undiagnosed for 5 years. Repeated attempts for care but OVCA went undetected.”

• “Was previously misdiagnosed with gall bladder attacks and was trying to save gall bladder by adjusting diet and doing detox treatments. Problem was with tumor in intestines.”

• “Being under 40 I was not as worried about breast cancer since my doctor had told me the year before not to worry about it until I was 50 since my mother and grandmother got in at age 50 and up.”

• “I didn't have a regular doctor or checkups. I told my sister about finding something new in my breast, and she told me to go to the doctor. I didn't, so she told our father, and they both insisted I go, so I finally went.”

• “Went for routine introductory care that Medicare offered. Probably wouldn't have done it if not for that exam offered.”
Most patient respondents (67%) were diagnosed at their first visit (including ER visits) for the presenting problem. On the other hand, 19% (10) had more than three visits before getting their diagnosis. Respondents attributed this to having to wait for a diagnostic procedure (2: bronchoscopy, colonoscopy); lack of finances to pay for care (2) or an implied failure to diagnose in a timely fashion on the part of the clinician (3).

**COMMENTS:**

- “I saw the chiropractor for 2 months (for my back) before he ordered an X-ray of my foot, which was also bothering me by then. That was abnormal, so he referred me to my orthopedic surgeon who ordered more X-rays, and an MRI and a PET scan, and then did a biopsy.”

- “I saw my PCP almost every month about my pain, and was given pain meds for it, until the pain got so bad I went to the ER in Garberville and the doctor there said my spleen was about to erupt. He sent me to Redwood Memorial in Eureka and I had surgery right away.”

- “I saw the VA doctor at least 5 times between 2012 and the time I was diagnosed in November 2013.”

- “I was hospitalized for 3 days because of my sodium level. After the X-ray it took 2 or 3 weeks for me to see Dr. X for a bronchoscopy and biopsy. During that time I had more visits with my doctor to keep checking my sodium levels.”

- “I first called the hospital myself to see how much an X-ray was, then went to my doctor to get a referral. After the first X-ray we knew something was there.”

- “After my doctor found something suspicious on my exam, it took two months before I had my colonoscopy. I had to call the doctor's office to ask/remind them about it.”

- “Was treated for symptoms believed to be GERD–cough, shortness of breath when lying down.”

Often there are several medical providers involved in the diagnostic process, which is another area where patients might experience delay or "get lost", and where a Navigator might help.
When asked how many doctors/providers they saw before their cancer diagnosis was confirmed, fifteen (28%) of respondents saw only one physician, twenty four (44%) saw two, and fifteen (28%) saw more than two.

**providers seen before cancer diagnosis was confirmed**

- 28% saw only one physician
- 28% saw two physicians
- 44% saw more than two physicians

**Comments:**

- “As I recall, my primary physician reviewed with me the results of the mammogram and ultrasound. She then referred me to Dr. X (surgeon). She felt starting with Dr. X was best....less chance of too much information from various sources and thus confusion.”

- “I was seen in Garberville at the clinic there, then at the ER in Garberville before being referred to my surgeon in Fortuna.”

- “My primary care doctor and MRI doctor, and emergency room doctor.”

- “First I saw a nurse practitioner, then I was referred for a mammogram and then for a lumpectomy by a local surgeon.”
(comments cont’d…)

- “I didn’t really see my PCP for this problem, but discussed it with him on the phone. He’d gotten my scan results from my Redwood Memorial ER visit. I was too far away to come in to his office to hear the results. He referred me to Dr. X (oncologist) that day.”

- “My GYN had made an appointment for me with a local surgeon at the same time as referring me for the mammogram and ultrasound. When the ultrasound was abnormal, the radiologist told me I had a choice: to have a biopsy right there, or to see a surgeon. I already had the surgeon appointment and I thought, ‘Oh, just take it out.’ I didn’t realize what that would mean later, and I wish now I had done it differently.”

- “I asked for a referral to a surgeon, when my internist didn’t feel the lump we both felt was something to be concerned about. I was 30 years old at the time.”

- “I saw two doctors in Crescent City, then more down here in Eureka.”

- “Dr. X who left on vacation did not push to get me diagnosed because I was uninsured at time.”
Once a suspicious finding has been discovered and a diagnostic test performed, there can be a period of waiting while the results are pending. We asked our patient/respondents if they experienced this, and if so, for how long.

<table>
<thead>
<tr>
<th>%</th>
<th>Number</th>
<th>Time Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>39%</td>
<td>21 of 54</td>
<td>one to two days</td>
</tr>
<tr>
<td>31%</td>
<td>17</td>
<td>less than a week</td>
</tr>
<tr>
<td>28%</td>
<td>15</td>
<td>one to two weeks</td>
</tr>
<tr>
<td>2%</td>
<td>1</td>
<td>more than two weeks</td>
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</table>

These are encouraging results, since in surveys elsewhere one of the major sources of anxiety for patients is the wait to learn whether they have cancer or not. In this survey sample, 70% of participants received their results within a week. The comments do remind us that giving important information to a patient as they emerge from sedation/anesthesia can be less than optimal (although another comment was critical of waiting for an appointment to discuss results) and that clinicians should be sure to introduce themselves before performing a procedure.
COMMENTS:

- “I was told when I went in to be biopsied that I had less than a 3% chance of having breast cancer. Initially the doctors thought I had a phyllodes tumor. My cancer did not present as breast cancer on the ultrasound.”

- “I saw Dr. X in Fortuna and she got me on the table the next day. After my surgery she explained about my cancer diagnosis.”

- “Biopsy was done by a stranger in street clothes. This made me nervous.”

- “I got the results right away. The whole cancer program here is incredibly well done! I've had no delays.”

- “My surgeon's staff came to see me the day after my operation and they told me what was found. And my surgeon showed me photos from my surgery. But it took almost a month after that for them to find out where the original problem started.”

- “My breast cancer was diagnosed and treatment (lumpectomy) began within a week. I decided to deal with the breast cancer first. For the ovarian cancer, I had my PET scan 2 months after the problem was found, but I delayed getting the PET results until we returned from a trip to Mexico. This was my choice. When we got home, we were notified of the results and saw the oncologist the same week. She referred me to the surgeons.”

- “They found a large tumor at my colonoscopy and they told me as I was waking up just afterwards.”
Learning they have been diagnosed with cancer is a charged moment for most patients. We inquired about how well they understood their diagnosis when it was first presented to them.

- Sixty-five percent (36 of 55) of participants responded “yes, I completely understood it.”
- Thirty-one percent (17) chose “yes, I understood some of it.”
- Four percent (2) answered “no, I didn’t understand it at the time.”

It is good to find that most respondents “completely understood” what they were told of their diagnosis initially. Their comments (below) reflect that in retrospect they learned additional details later as more information became available, and that having another trusted person present when crucial information is being conveyed is helpful (especially if the patient’s consciousness is impaired).
• “Dr. X (oncologist) is great is coming up with ways to talk to patients to tell them what's wrong.”

• “He explained things very well.”

• “Parts of it I don't remember because I was on pain meds after surgery, but my father and aunt were there when we talked to the doctors, and they explained it to me afterwards.”

• “I thought so at the time.”

• “I understood as much as I wanted to at the time. I chose not to ask many questions at the beginning of treatment. I've learned more since my transplant.”

• “I understood that I did have breast cancer and that it was caught early stage. Per Dr. X the next step was a lumpectomy and that this would indicate what further treatment would be (chemo, radiation, etc.). I prefer taking one step at a time....let's deal with this procedure and then go to the next. Going too far ahead just causes further anxiety.”

• “They told me as I woke up. I thought then, ‘Let's find out how you get rid of it.’”

• “The doctors initially told me that I had a cyst. In actuality I had a very rare type of breast cancer that appears like a cyst on the ultrasound.”
Our patient/respondents were initially diagnosed at different cancer stages:

**CANCER STAGE AT DIAGNOSIS**

<table>
<thead>
<tr>
<th>Cancer Stage</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage I</td>
<td>17%</td>
</tr>
<tr>
<td>Stage II</td>
<td>22%</td>
</tr>
<tr>
<td>Stage III</td>
<td>19%</td>
</tr>
<tr>
<td>Stage IV</td>
<td>22%</td>
</tr>
<tr>
<td>Don't know/Can’t recall</td>
<td>20%</td>
</tr>
</tbody>
</table>

Their comments reveal some confusion on this point:

**COMMENTS:**

- They haven’t given us a stage yet. It’s one of our confusions. From our reading we know it’s not stage 4 but when we don’t get a clear answer when we ask.
- “I still don’t know.”
- “I don’t know. I didn’t ask.”
- “I was never told what stage it was.”
The next question on the survey asked, "Did your primary care provider offer written information about your cancer, or suggest other sources of information?" The wording of this question produced somewhat misleading results. We assumed that patients would be receiving their initial diagnostic results from their PCP, whereas in fact most respondents were given their cancer diagnosis from their surgeons and oncologists. This may have contributed to some of the “no” responses on the survey.

The results:

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<table>
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<tr>
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</thead>
<tbody>
<tr>
<td>47%</td>
<td>25 of 53</td>
<td>“Yes, I received all the information I wanted.”</td>
</tr>
<tr>
<td>21%</td>
<td>11</td>
<td>“Yes, I received some information, but I wanted more.”</td>
</tr>
<tr>
<td>30%</td>
<td>16</td>
<td>“No.”</td>
</tr>
<tr>
<td>2%</td>
<td>1</td>
<td>“I did not want any more information.”</td>
</tr>
</tbody>
</table>

Again, the comments also reflect that patient’s comprehension can be limited post-op or when first presented with bad news, and in these circumstances patients may not know what questions to ask. A Patient Navigator could be helpful here for some patients.
• “I never returned to my primary care doctor’s office again. I saw Dr. X (surgeon) and Dr. Y (oncologist) from the point of diagnosis onward.” (This patient’s PCP had delayed working up what proved to be cancer.)

• “It was pretty rushed and we were flabbergasted. Every time they did a new scan they told us there were more spots of cancer, so it seemed like it was spreading pretty fast.”

• “We did look online for ourselves but you can't always believe the Internet.”

• “Dr. X (oncologist) gave me a bunch of information he ran off for my particular lymphoma.”

• “I don't believe in “too much information”--I think knowledge is power.”

• “I didn’t see my PCP after having the mammogram, but my surgeon and his staff gave me all the information I wanted. I had several visits with him to discuss my options. I cannot say enough (positive) about him and his staff! Also, my radiation oncologist gave me a huge packet of information.”

• “I received information from the gynecologist, not my primary care doctor.”

• “I got lots of information about SIADH (the cause of my high sodium level) but not so much about small cell lung cancer.”

• “I called and was supported by the North Coast Breast Health project.”

• “My initial provider/surgeon did not. I came to Dr. X (surgeon) for a second opinion and switched my care to her. She was great with all the info she provided.”

• “It's hard to remember. I was also going through the choice of whether to amputate my left leg or try to save it. I didn't really understand what kind of cancer I really had. My oncologist was really good about answering questions. I just didn't know which ones to ask.”

• “I couldn't read it. I was disoriented and afraid.”

• “They talked to us after surgery but I don't remember receiving much specific information until we talked with the oncologist 2 or 3 weeks after the surgery.”
• “My surgeon recommended Dr. Susan Love’s book (although it was hard to find a copy; I had to order it online).”

• “I got written stuff after seeing an oncologist. Thank God for the internet.”
After learning the diagnosis, patients presumably wish to consider treatment as soon as possible. We asked how long it took for them to see a cancer care specialist to discuss treatment options.

The results:

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3 DAYS</td>
<td>15 of 53</td>
<td>48%</td>
</tr>
<tr>
<td>3-7 DAYS</td>
<td>9</td>
<td>17%</td>
</tr>
<tr>
<td>1-2 WEEKS</td>
<td>18</td>
<td>33%</td>
</tr>
<tr>
<td>2-4 WEEKS</td>
<td>11</td>
<td>11%</td>
</tr>
<tr>
<td>&gt;1 MONTH</td>
<td>11</td>
<td>11%</td>
</tr>
</tbody>
</table>
At first glance, it appears that 44% of respondents saw an oncologist within a week of diagnosis, and 78% within 2 weeks. But reviewing the comments, we find that some apparent delays were to allow healing from surgery before initiating further treatment, and some were due to diagnosis and/or treatment out of our area.

COMMENTS:

- “With my prostate [in the Bay Area], I saw someone the next day. With my lymphoma [Humboldt County] it took about 2 weeks.”
- “My surgeon [in San Luis Obispo] discussed it with me after my operation. My roommate drove me and my daughter up here [from Southern CA] about ten days after that to see Dr. X (oncologist).”
- “My oncologist arranged for me to see the surgeons for my ovarian cancer. My regular physician referred me to Dr. X (surgeon) for my breast cancer.” (This respondent reported 3 to 7 days for this to take place)
- “I had multiple visits with my surgeon to discuss my treatment plan, and had a lumpectomy and sentinel node biopsy. I didn’t see an oncologist until about 2 months after I was diagnosed, because I needed to heal from my surgery and also I had longstanding plans involving my family that I wanted to follow through with. This was completely my decision, not due to any delay in the referral process. “[This respondent reported more than a month].”
- “The skin person in Eureka and I were trying to figure out the best place to go; then it took a bit of time to get an appointment.” (This respondent reported “more than a month”)
- “I had to heal from the hysterectomy that was the final detection mode. And my oncologist was very busy.”
- “It was very hard to wait for almost five weeks to get an appointment in San Francisco.” (Endometrial cancer. “More than a month”)
- “Dr. X (oncologist) gave me the choice of beginning treatment with hospitalization here on the day of our first visit, and I agreed.”
- “At the time, he was the only oncologist in Eureka. And, I was never made aware by him or his office that he was ‘out of network’ with my insurance.”
- “The receptionist was going to put me off for a couple of weeks, but the doctor overheard the phone conversation and could tell I was distressed and got me in right away.”
(comments cont’d...)

- “I had to have a second surgery because the margins were not clear from the first one and the surgeon also hadn’t taken out any lymph nodes at first. My son wanted me to see an oncologist, and he arranged for me to see Dr. X (rad onc) right away. Dr. X was wonderful and spent a lot of time going over my situation with me even though I didn't actually need radiation treatment at the time. I saw Dr. Y (surgeon) after talking with Dr. X, and I then saw Dr. X (oncologist).”

- “Was checked into the hospital within a week. But a last-minute X-ray failed to show the tumor. Was discharged. Later, when the cough returned, another X-ray showed the tumor. Was checked in again for surgery. I first had to get a biopsy, then a cancer board following week, then it was wait to see an oncologist. Too long.”
Making decisions about cancer treatment options can be complex. To quote Cancer.Net* an online information site of the American Society of Clinical Oncology:

"After a diagnosis of cancer, patients and their families have to make a number of decisions about cancer treatment, some of which are more difficult than others. These decisions are complicated by feelings of anxiety, unfamiliar words, statistics, and a sense of urgency."

Patients differ in their approach to treatment decisions, some taking a passive role, others a very active one. Many follow a mix of approaches. We asked patients what sources they used in thinking about their treatment options, using a 1 to 4 ranking scale with 4 being the most important.

<table>
<thead>
<tr>
<th>ONCOLOGIST'S RECCOMENDATIONS</th>
<th>FRIENDS &amp; FAMILY</th>
<th>LOCAL SUPPORT ORGS</th>
<th>OTHER ONLINE SOURCES</th>
<th>ALTERNATIVE RECOMMENDATIONS</th>
<th>AMERICAN CANCER SOCIETY</th>
<th>NAT'L CANCER INST</th>
<th>BLOGS/TESTIMONIALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.8</td>
<td>2.7</td>
<td>2.7</td>
<td>2.6</td>
<td>2.5</td>
<td>2.2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

“I relied on my oncologist’s recommendations” was by far the source most used by respondents, (190 points on the ranking scale)

“Friends and family” came next (112), followed by “local support organizations” (81) and “other online sources” (74).

The ACS ranked next (68), followed by “complementary/alternative medicine recommendations” (61). “Online blogs” (49) and the NCI (45) were ranked lowest as sources of information used. We include many of the comments to this question, as they illustrate vividly how these moments in the "cancer journey" affect patients and their families.

COMMENTS:

- “I saw Dr. X (holistic physician) and was very impressed with what she said about diet and supplements initially, until I was actually in treatment. I couldn't follow all her dietary advice because I had to gain weight. I didn't take the oncologist's advice as gospel; I disagreed about the cisplatin until I learned more about the alternative. I was really looking around for a way to avoid chemo, and my son strongly advised me against it, recommending hemp oil instead. I used that for about 2 weeks but it was kind of difficult because of my reaction to it. The most significant source for me was people who'd had the same diagnosis, who I found by word of mouth. Their experience did more to help me decide to proceed with the treatment than any other sources. This source doesn't have to rely on local people only. My contacts were over the phone, and the Cancer Society has a place to find people with the same diagnosis.”

- “I was diagnosed with a very rare type of breast cancer. Around 1% of women will have this kind of breast cancer, so I did extensive research about the type of cancer I had. I found an online support group for women who had the same kind of cancer. It was helpful for a while until women were dying left and right. I was able to receive support from the HCBHP. This was a great source of encouragement and strength for me. I attended their support group, but again, the stage 4 patients scared me away.”

- “My son has bone cancer (but not myeloma) so he's going through some of the same experiences. I did consider homeopathy, and some of our friends have gotten cured of their cancer without using chemo or radiation.”

- “I relied on my primary care provider's recommendations --very important.”

- “I'm not going to pre-empt my doctor.”
• “I listened to my doctor. I didn't have any idea what to do. My friend who has had cancer himself also has been with me at my appointments.”

• “I looked at many sources about prostate cancer (including ACS and NCI). My daughter, a PA who worked for a urologist, gave me lots of information and I also looked online, although there's a lot of misinformation out there. Johns Hopkins' literature on prostate cancer is very good. With my lymphoma, I trust my doctors, and my daughter tells me there's really no alternative besides what I'm doing. So I haven't done that much reading this time.”

• “I rely on my primary care physician to guide me, and she's working very closely with my oncologists. I feel they're all working together as a team. And I'm a computer dummy, so I didn't use online sources.”

• “I relied very much on my surgeon's recommendations: he was very thorough in presenting my options to me. I did look at online blogs and such, but I had to quit reading them: they left me hysterical (confused and anxious).”

• “I wasn't far enough along and not smart enough to use the resources that were out there. I did go to the Breast Health Project.”

• “The Humboldt Community Breast Health Project had a computer program which involved an ‘interview’....discussion of my thoughts, fears, long-term wishes, etc. The "results" better enabled me to see the whole picture - how I saw my life and how the cancer treatment options fit in. Dr. X’s (surgeon) review of these results enabled her to see this also. So we were all on the same page.”

• “My surgeon - most important.”

• “I am a Native American, and we have fire pits and other healing ceremonies. I live off the grid and have never used a computer in my life.”

• “At first I was really lost and didn't really know where to turn. Since then I have received a lot of information and support from the Facebook page Sarcoma Alliance that I found through Amputee Coalition of America FB page.”
(comments cont’d…)

- “People tell you wild stories...you don't want to listen to them. I don't do anything online.”
- “I don't have a computer and don't know how to use it.”
- “Due to rare cancer, I chose to do many hours of online research to find top doctors/programs in the nation. I was recommended to an oncologist in the bay area that is a specialist in this cancer - and closest to home, but I chose to go to a hospital where a whole program with a team of doctors were dedicated to this study/treatment of this cancer. Travel expenses are more, but I felt this was my best chance for quality of life/survival.”
- “There aren't any local cancer support organizations in Crescent City.”
- “I don't have computer access. There aren't any local organizations here (Del Norte) that I know of.”
- “I have a family member who is an oncologist that we talked to.”
- “A nurse suggested visiting Santa Rosa, where Jos. Simonton was scheduled to speak about guided imagery. The nurse, my wife, & I drove down. I used his procedure to supplement chemotherapy, and have since used guided imagery with cancer patients.”
- “My partner and her sister and my sister being doctors were extremely helpful. Breast Health project let me join their poetry project. American Cancer Society had support group I went to a couple of times. Not really for me. Lots of people gave me unsolicited ‘avoid conventional medicine’ advice and testimonies. I had already decided to do chemo and these were most frustrating.”
As some comments reflect, not everyone locally has computer access or skills to enable information searches online (this may also reflect the ages of the participants). Thus, while some patients searched online extensively, looking at "official" sites like the ACS and Johns Hopkins as well as online support groups of people with similar diagnoses, others found some of what they found to be disturbing and not helpful, and some could not use online sources at all.

Respondents also consulted friends and family members, mentioning especially those in healthcare professions. The Breast Health Project was frequently cited, both for its support groups and its computer programmed "interview". Talking with others who have been through a similar experience, as in an ACS support group or the Breast Health Project, was valuable to many. Such groups are less accessible to those living away from Humboldt Bay, but as one participant with an uncommon cancer found, sites like the ACS can help connect people with similar diagnoses online wherever they live, and phone conversations can be very helpful as well. On the other hand, some found that unsolicited "advice" from acquaintances was unhelpful.

The comments also reflect a spectrum of approaches to this question: from those who simply say they relied on their doctors' guidance alone, to those who "chose to do many hours of online research". This is an area where a Patient Navigation program could prove very valuable, perhaps offering computer search access and guidance for those who want it but lack the means, or facilitating connections between people sharing similar diagnoses, transportation to support groups etc. But such a program should also allow for the fact that not everyone WANTS more information.
Looking further at this question of the amount and quality of information desired by patients, we asked, "How do you feel about the information available to you when you decided about your cancer treatment?"

- 54% of respondents chose “I am comfortable with the amount of information available to me.”
- 13% “would have liked help in finding more information or in making sense of it.”
- 11% “wanted more information than was available to me.” So a total of 24% wanted help.
- 7% “felt there was too much information available to me.”
COMMENTS:

- “I wanted more information from people with the same diagnosis”

- “Sometimes when we ask questions after we read things online the oncologists react as if we are challenging their expertise which isn't true. We just want to understand.”

- “There was so much information and I could absorb only absorb so much.”

- “I deal with this situation segmentally, a little at a time.”

- “I think that mostly I was overwhelmed and didn't know what questions to ask. It might be helpful for a Frequently Asked Questions page to be handed out to first time cancer patients.”

- “Being overwhelmed is very different from being mentally ill. The only offer of assistance I received was a woman telling me she was there to assist me with my mental health issues. My first reaction was to be angry, then I decided the poor thing didn't know what she was doing.”

- “I thought I was going to die so I didn't care.”

- “I was overwhelmed with the amount of information. It was all just too much, and I quit reading it.”

- “I am comfortable because I spent many, many hours on the internet researching and talking to people. My family also helped me research and so my treatment decision was easy. I think other people in my situation may not have been as inclined, confident, or educated about options and this is where a Navigator could be very helpful for less assertive folks. They deserve to know all viable options.”

- “My online searches confirmed what I was told by my oncologist. He didn't leave anything out.”

- “The info/pamphlets were written on a sixth grade level. I needed more explanation of the why, more science and depth.”

- “Took a while for it to come out from providers.”
These comments again reflect the varied needs and feelings of patients facing this challenge. While most were comfortable with the amount of information available (whatever sources they consulted), there were those who felt overwhelmed by it. Some found their doctors to be excellent sources, reinforcing what they found online, but one felt his/her questions based on online sources were perceived as challenges by their oncologists.

The suggestion of a "FAQ" page "to be handed out to first time cancer patients" is interesting to consider for use in our Patient Navigation program. And the respondent who remarked, "Being overwhelmed is very different from being mentally ill," and was put off by having someone offer "to assist me with my mental health issues," makes a good point as well. The navigation assistance we offer must be mindful of how we offer it. As for the respondent who wrote, "I think other people in my situation may not have been as inclined, confident, or educated about options and this is where a Navigator could be very helpful for less assertive folks. They deserve to know all viable options," this is a fine suggestion for our Program as well.
Another way we posed this question was to ask, "Did you receive sufficient information about the advantages and disadvantages of different treatments, so you could make a proper choice?"

- 69% of respondents said “yes.”
- 15% chose “yes, but I needed to search for it myself.”
- 15% said “no, I would have liked help.”
COMMENTS:

- “Again it's hard to recall how it was in the beginning, but mostly it felt like, ‘here is what we are going to do.’ or ‘I think this would be best’ followed by ‘do you have any questions?’ and I didn't know what to ask or what I should be asking.”

- “We really took our doctor's word for everything but it would have been nice to have had help finding out more.”

- “The Breast Health Project gave me a binder full of information on this, but I had no idea that I would actually suffer so many of the side effects. Guess I was under the impression that they were slim possibilities, such as what you read on inserts about prescriptions. I didn't realize there was such a high likelihood of being permanently affected by some of them (lymphedema, neuropathy), or temporarily affected by others (blood clots, for example). Before I had cancer, I thought hair loss and nausea were the only side effects.”

- “Even with the Stanford consult, I wasn't presented with enough to make a choice. Especially looking back, I knew very little then, and I was given choices to make with very little basis.”

Almost 70% of respondents answered "yes" to this question, which is good. But, again, 15% felt they needed to do more investigation themselves, and another 15% would have appreciated help in such a search. A Navigator could help here.

There appears to be some confusion regarding "choices" and "options". Some respondents felt they had no choice of treatments, others suggest that if there were other treatment options, they were not brought up. And even when provided with "a binder full of information" about side effects, at least one respondent didn't appreciate the likelihood of experiencing them herself until she did.

Again, the observation "I didn't know what to ask" suggests the using a FAQ approach, particularly given that these questions may arise with a sense of urgency, a need to decide on a treatment plan expeditiously.
We then asked patients whether they considered other sources of care before starting their cancer treatment.

- 54% (29 of 54) No, did not consider other possible sources of care
- 33% (18) Had a consultation/second opinion out of area
- 9% (5) Saw a CAM practitioner
- 4% (2) Wanted another opinion but circumstances did not allow it
A little over half of the respondents did not seek/were not referred out of the area for treatment. Thirty-three percent did leave the area at some point. Of these, from their comments, half appear to have sought a second opinion themselves and half were referred by our local oncology program for a second opinion or for therapy unavailable locally.

It's good to hear patients' satisfaction and confidence in our local program, and that this has been reinforced by the advice of tertiary centers.

The nature of our recruitment of participants in this survey could tend to underrepresent local cancer patients who do not choose "conventional" therapy. We did contact one naturopathic practitioner in Southern Humboldt, looking for patients who were using only CAM, but he said he rarely if ever saw patients who chose only this. Further research into how and why cancer patients locally consult/ are referred to CAM practitioners would be of interest; we suspect our sample result of 9% reporting this may not completely represent those who include this treatment pathway.
We next asked our patient/respondents about the factors that influenced their decisions about treatment choices, and also to rank the importance of each factor (from "most important" to "not at all important"), which we converted to a scale from 1 to 6, with 6 being most important.

- Trust in my doctor: 5.6
- Trust that the treatment would be successful: 5.4
- Worry about the side effects of treatment: 4.2
- Advice from my friends/family: 3.6
- Financial/insurance coverage to pay the costs: 3.4
- Transportation to & from treatment: 3.3
- Responsibilities as a care provider: 3.1
- Other life issues were more important: 2.5
- Need to keep my job: 2.5

While this tabulation shows the three factors at the bottom of the list scored lowest overall, it is worth noting that 3 respondents ranked "care provider responsibilities" as the most important factor for them, one chose "need to keep my job" as most important, and 2 said "other issues in my life" were the most important factor in making their treatment decisions, so these should not be discounted for individual patients.
“Transportation was somewhat important in that going to Stanford for ongoing treatment would be challenging.”

“I was recommended to take Lupron for a year, but it really flattened me. My mentation is where I live. So I decided to take the Lupron for only 3 months. And we cut my vincristine dose in half because my hands were getting numb. (I’m a sculptor, a photographer and a woodworker). But this is also kind of scary.”

“I didn’t really think a lot about whether the treatment would work. I didn’t allow myself to think about that because everyone reacts to treatment differently. Quality of life was the most important thing.”

“I was terrified of chemo, especially about losing my hair.”

“I have a daughter with MS who has 3 children, and my parents are in their 80’s. I take care of them, and my daughter and grandchildren (and my husband) take care of me. This is top priority.”

“My father-in-law was living with us when I was first diagnosed. After we suspected the ovarian cancer, and realized what was in store for us, we moved him to my brother-in-law's (his son). I kept my job during my early treatment. I think I needed a reason to get up and put my shoes on in the morning, and I had a lot of flexibility at my job as well as a lot of sick time accrued.”

“I never questioned that the treatment would work. I had some side effects from my treatment, but it is what it is. I've had to move temporarily from my home in Bridgeville to Eureka during my cancer therapy over the past 2 years in order to be able to get treatment. And I've been down to Stanford 4 times, staying as long as 31 days there. Good friends have driven me and shared their home in Eureka with me. Otherwise I would have had to stay at home Bridgeville on my own.”

“I very much would have liked to keep my job as a one-to-one aide for children with autism, but the cancer caused me to lose mobility needed to do the job.”

“Transportation was important because I don’t drive. My husband could at first but now my daughter has to take a day off of work to drive me. Side effects were not important because that's the only way I would survive. I quit my job when I got sick.”

“I went through a lot of anxiety worrying about side effects.”
• “I lost my husband during the time I was first diagnosed with cancer.”

• “My daughter’s sudden death just after my lumpectomy interrupted my thinking about the rest of my treatment.”

• “I had a surgical and a radiation option. Each was quoted as having equal probability of success. However, knowing whether the treatment worked was very important; surgery would get an answer fast. Also, if surgery failed, radiation was a fallback, while radiation doesn’t allow surgery as a backup. In the event, I needed both options.”

• “I had complete trust in my doctors.”

• “Quality of life after treatment was a major consideration
Most patients (82%) found supportive sources of information and resources in the community:

(Some respondents chose more than one location where they found information.)

- Yes, at my doctor’s office 22%
- Yes, at the oncologist’s office 49%
- Yes at a support organization 39%
- No, but I would have wanted to 14%
- No, I didn’t want to 10%
Often respondents mentioned a particular person: a nurse in the chemo suites, a social worker, someone in the oncologist's office. Also cited was the Humboldt Community Breast Health Project, as well as case managers from insurance companies. But not everyone found it easy to access services:

**COMMENTS:**

- “A couple of friends mentioned that there were some programs that may help with my transportation costs out of the area, but I did not have anyone approach me to see if I had any special needs/problems. During this time, my husband was very ill and my life had been turned upside down. There was a case nurse that works for my health insurance company that called me and informed me that my insurance would pay for a couple of visits to a psychologist/counselor.”

- “(An oncology nurse) in Eureka has been very helpful but there's nothing in Crescent City. Nada.”

- “A friend told me about the gas card available from ACS, but I had to find out about Disability programs myself. Brookings has a cancer thrift store that can help with wigs, but I found that myself as well.”

This looks to be an area we could improve on, when the Comments are taken into consideration.

While over 80% of respondents did get advice about available local resources and support, it does not appear to be always and routinely offered within St. Joseph's Cancer Program. The Comments remind us that some support can be available under health insurance plans. Our Navigation program should include this resource for eligible patients, and perhaps investigate how to access this efficiently. Also, our program should facilitate sharing of resource information from the various experienced people currently involved.

Ideally, having a social worker routinely scheduled to see all of our cancer patients seems like a good goal, or perhaps this is another role for our Patient Navigator. Needs can arise all along the care continuum, and once a patient has met with such a professional, at least they now have identified someone personally as a source for supportive information.
The period between the patient's first oncology consultation and the start of treatment is another potential measure of care quality, although there are other factors that can impact this: the need to recover from surgery or the time required to arrange for out-of-area consultation, for example. So the responses by patients when asked how long this took need some interpretation:

<table>
<thead>
<tr>
<th>Duration</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 to 3 days</td>
<td>10%</td>
</tr>
<tr>
<td>3 to 7 days</td>
<td>15%</td>
</tr>
<tr>
<td>1 to 2 weeks</td>
<td>44%</td>
</tr>
<tr>
<td>More than a month</td>
<td>31%</td>
</tr>
</tbody>
</table>

![Pie chart showing the distribution of the duration between the patient's first oncology consultation and the start of treatment.](chart.png)
COMMENTS:

- “About 6 weeks. This was partly due to my reluctance to do it at all, and then my reluctance to cisplatin initially. After doing more reading I decided to go with the cisplatin after all. I also took an extra week to go to see plays in Ashland”

- “It took three weeks: The other medications I was on when I was diagnosed would have interfered with my cancer treatment, so I had to stop them and switch to different ones before I could start.”

- “As a single parent with a minimum wage job and also a full-time student, I was getting Food Stamps and MediCal in San Luis Obispo. It took a while for them to transfer the MediCal authorization up here so I could start treatment.” [1-2 weeks]

- “Actually, it took 4 months after my surgery for my radiation therapy to begin. The Tumor Board suggested genetic testing could influence which treatments I might choose. It took a while to get my insurance approval and arrange the testing, which resulted in a delay, but the results greatly influenced the final plan: I chose not to have chemo, which would have only changed my odds very slightly. This way I won’t have the chemo side effects, like hair loss. I am going to have hormonal therapy though.”

- “I was admitted to start treatment THAT DAY!”

- “My treatment would have started locally here within a week or so, but needing an MRI was making the wait longer. They were waiting for menstruation, but it was not going to happen because I had been given a drug that was preventing its occurrence. One of the reasons I left the area.”

- “Selecting and being accepted, scheduled by my surgeon. Total, mid- December thru end April, actual surgery May 3.”

- “Obtained 2nd opinion before getting 1st Lupron shot. Was diagnosed in May and radiation treatment didn’t start until November.”

These results show 69% of respondents began their treatment within 2 weeks of diagnosis, and their Comments suggest that, for those who waited longer, this was often due to the need to recover from surgery first. Also patients who had out-of-area consultations or testing done experienced delays. Some of the comments suggest that "arranging" or "scheduling" appointments, tests, or procedures took a while, but none of the respondents expressed concern or regrets about this.
Patient/respondents overwhelmingly said they felt involved as much as they wanted to be in decisions about their care and treatment:

- Yes, definitely 87%
- Yes to some extent 9%
- No would have liked to be more involved 2%
- Not sure/can’t remember 2%
COMMENTS:

- “Very much involved. Besides my discussions about the cisplatin, I also talked with Dr. X (radiation oncologist) about how many rads to give me and he agreed that I could make the choice. I ended up choosing the full treatment they recommended.”

- “Sometimes I don’t know what kind of questions to ask. My father and my roommate ask good questions for me, but I would appreciate a list of important questions other people like me have asked, like a FAQ.”

- “I was in total control.”

- “I guess so. She always asked if it was OK, but what did I know about any of it? Nothing.”

- “I think that I could have been better informed about why I was getting a treatment. I knew it was a common treatment for my type of cancer, but it wasn’t really discussed with me why.”

- “I was an advocate for myself after the medical system had let me down. I told my doctors here that if they didn’t give me the chemo plan the doctor at Stanford gave me I would have my treatment done at Stanford.”

- “Informed consent forms were offered, but there was no oral explanation prior to surgery. Some side effects of chemo not discussed at all, ergo cognitive effects.”

Overall, the great majority of respondents report feeling satisfied and positive about their involvement in their treatment decisions. But some of the Comments suggest areas for improvement, where communication between patient and physician felt less than what the patient wanted. Again there's a request for guidance in knowing what to ask, an "FAQ". A Navigator could help with this.
We asked patients about what problems they experienced during their cancer treatment, and if possible to rate them by how challenging they were, using a 1 to 5 scale, with 5 being “most important” and 1 being “not very important.” The scored results:

- Side effects of treatment 172
- My emotional state 155
- Worries about my family 146
- Uncertainty about the future 146
- Keeping track of insurance bills 106
- Keeping track of medical records 99
- Keeping track of medical appts 94
- Keeping track of meds & refills 91
- Shopping/preparing meals 91
- Housework & laundry 90
- Spiritual concerns 89
- Other people’s reactions to my illness 85
- Transportation to appts/treatments 84
- Need to keep my job 53
- Transportation to friends, church, shop 48
The nausea caused by my chemo was very significant, and led me to discontinue chemo after 5 treatments instead of the 6 originally planned. (My oncologist agreed with this.) I think better communication and clarification with patients about their medications is needed. During my treatment I was given 3 different prescriptions for nausea, all from my oncologist, to see which would work best. I didn’t know when to start taking them: if I was already nauseated then I couldn’t keep it down. I eventually got a suppository from Dr.(X) which helped, but I felt if had had been given a regimen for when to take the pill with respect to the chemo, it might have prevented the nausea, which was the worst part of the treatment. Regarding other people’s reactions to my illness, I was mostly concerned about bringing up THEIR cancer experiences: my daughter-in-law had just lost her father to cancer, and I didn’t want to upset her. My wife took care of keeping track of things like appointments, medications and records. Regarding my emotional state, I was largely just kind of dazed during this time.”

“My hands and feet are more sensitive since I started treatment. I’m a private person, but my friend blabbed about my cancer right in the middle of a store, and now everyone knows, and people treat me differently. At first housework and meals was a problem, but they hired live-in home support for me so it’s OK now. I do worry about my family, my kids--they almost lost their mother! It makes me want to go get a will. I made an appointment twice for it, but it’s the only appointment I've missed. Since I got sick, a lot of religious people have come to see me.”

“My wife takes care of keeping track of the bills, the medical records and the appointments, and it's challenging to her. Keeping track of my oxycodone and Lunesta are very important to me. I didn’t cook or do the housework before I got cancer. My emotional state has been very intense and it hasn’t stopped being so up to now. I want to be able to do what I do--sculpture, furniture restoration--so the side effects of my treatment have been a big concern.”

“I didn’t realize how important it was to take Prilosec and eat before taking my chemo, so I ended up in the ER the second week into treatment. As long as I don’t have to drive myself from Weitchpec and the weather is OK, transportation to my medical appointments isn’t too bad, but the gas is expensive, so my roommate and I are going to look for a place in Eureka to be closer. My boss has been really helpful & I can go back to my job whenever I'm ready. I realize that I have to take precautions while I'm on chemo: you have to make sure that your family & friends know what they need to be careful of, like being around me when they are sick. Right now we're living in a house with 9 people. I want to take care of things so that my daughter is comfortable. About my future: I like how my daughter is now--she's only 6 but she reads at a 5th grade level--and I would want her to live with my cousin if something happens to me. My cousin is very successful, smart and logical, but she's not soft at all, which concerns me.”
• “Keeping track of records between three doctors, two labs, several places for scans, and all the insurance was difficult!”

• “I have had 3 recurrences of my ovarian cancer, and 3 different chemo regimens, as well as 2 courses of radiation. The side effects have differed over time. Receiving treatment at UCSF involves staying in motels there, sometimes for 5 days at a time, home for the weekend, and then back for another 3 days; this happened regularly for a while. We had a favorite motel there that sometimes was affordable, but lately SF has gotten so expensive that we stay in Santa Rosa. Just for a doctor's visit there we have to stay 2 nights. The Breast Health Project taught how to handle the bills, and now that I’m on Medicare it’s easier.”

• “I live alone and my cancer treatments were pretty basic. Other than the lumpectomy, I drove myself to radiation treatments and oncology appointments. I did not have and still have not had really serious side-effect issues, so I have been able to take care of myself. I do have relatives close by should I have needed them.”

• “The side effects were terrible, but transportation has been the biggest challenge. I'm on a high dose of prednisone so I can't drive now, and friends have to do all the driving for me. I had a close friend who took charge of many details when I was first being treated. When she left I had to do more myself, keeping track of appointments and medications. I use a "back-up brain", a daily log where I write everything down. As for my emotions, I sometimes get the "what ifs" in the middle of the night, but I remind myself that I'm on prednisone (that can change how you feel).”

• “I think that above all I worry about my child and spouse. Even though my daughter is 18, a girl still needs her mother always. I have had a really hard time organizing all the different bills. All those envelopes come so fast and so many, I just don't know what to do with them. The paperwork involved with having cancer is overwhelming.”

• “Regarding side effects, this wasn't really a problem because I was told what to expect. I didn't have to like it but I knew it was going to happen. As for transportation, it's been frustrating sometimes because you have to call people to bring you (for chemo) and take you home. I keep track myself of my appointments with a calendar, and they give you little cards. And I already had 2 ladies that do my house every two weeks, so that's not a problem now. There are days when you're frustrated, but you can't let that stuff interfere with your day.”
(comments cont’d…)

- “I wasn't sure I could handle the side effects. My daughter has to take me to my appointments and to shop. Other people's reactions are important: I don't want to hear that word ‘cancer’.”

- “I want to erase that in my mind. My daughter helps me with my bills and at home, but she is a single parent herself and has a job, too. At home I can't do much housework because I worry about my port, and my husband is 91 so he can't help me.”

- “I don't really think about my future I have made my arrangements already.”

- “Before and during treatment, I was concerned about my wife's feelings. Her first husband had died at age 30. She was worried while I was not. After the surgery, I was overjoyed to be alive. Later I described this feeling as getting my music back. Poetry poured out, about birds, a daughter's wedding, a sea otter & young, etc. Some of that poetry found its way into print.”

- Most patient respondents (67%) report that they received a treatment plan summary and information about its potential impact on their life.
- 67%  Yes, I received enough info & my questions were answered
- 15%  Yes, I received some info but I still had questions not addressed
- 13%  No, I had many questions that were not addressed
- 4%   No, but I did not want any more information

COMMENTS:
• “I did not receive information about the psycho social aspect of treatment.”

• “We didn't understand that the radiation wasn't actually curing my cancer, but was to treat my pain. We didn't realize I would have chemo, too.”

• “(I was) too confused at the time.”

• “I'm learning about it still. Everything I ask they give me the answer.”

• “It seems like my doctors mostly gloss over those parts. They don't talk much about long-term effects unless you ask them. For example, no one volunteered much information about my hormonal drug: not the oncologist, not the pharmacist. I only knew to ask about side effects because of my own reading.”

• “My oncologists gave me all the information I wanted. There are too many frightening things on the Internet.”

• “My oncologists work well together.”

• “They gave me as much information as they knew at the time, and I didn't want to know more.”

• “I do not remember receiving anything other than verbal instructions.”

• “As stated above, I wish someone would have stressed to me the high likelihood that I would have so many side effects. I realize not everyone has as many as I did, but I don't feel that this was stressed at all.”

• “My case went to the local tumor board and I was told I was inoperable and clinical trials were mentioned as a possible option. I was sent out of the area to explore this option. Only based on my research did I find that there are multiple treatment possibilities and I wouldn't have much hope if I had stopped based on what I was told. The options I'm speaking of are not far-fetched or considered unreasonable. It would have been good if I had been told of these possibilities and then referred out of the area. It was a pretty dismal experience for me. I don't blame local oncologist for not having the answers, but seems like the tumor board could have done a little more research and informed me of the various possibilities.”

(comments cont’d...)
• “They gave me a notebook. They could have given me more. I still don't have enough. When I asked how long will I be on chemo, my doctor said, ‘I have no idea.’”

• “One of the physicians said directly they wouldn’t answer my questions about suggestions in a book.”

We can aim to improve this as one of our goals. While 67% felt they had been given a treatment plan summary and that their questions were adequately addressed, that leaves another 32% whose needs were not completely met. Our Survivorship Program should help here. Since side effects of their cancer treatment were the biggest challenge noted by the respondents, improving communication about this makes sense.

The comments suggest that the information needs to be provided in multiple ways (both written and verbally), with thorough attention to both short- and long-term effects. Also, making information available all through treatment might improve the patient’s experience, as questions arise and information is wanted at different stages by different patients: possibly a checklist that follows the patient through the Cancer Program to document what has been addressed, when and by whom (even though such information may need to be reviews more than once).
A large majority of the patients felt that they had a clear idea of which health care provider was "in charge" of their care, whom they should call if they had a problem:

- 80% Yes, definitely
- 13% Yes, somewhat
- 7% No, and it can be a problem
- 0% No, but not a problem
A few comments do suggest the complexities that can arise:

**COMMENTS:**

- “Regarding my cancer care, sometimes I’m not sure whether to call my oncologist, my radiation oncologist, or my surgeon, but I feel they're all aware of what my treatment was.”

- “No problems, but maybe when my oncologist at UCSF retires.”

- “I have 5 doctors now--I also have Crohn's disease--and I don't know whether all my doctors have access to or receive notes about my progress.”

- “When I developed cellulitis shortly after finishing my chemo, I didn’t really know which doctor to call.”

- “My oncologist practiced in 2 towns, and appointments were sometimes bobbled.”

- “I have had issues at Stanford.”

- “My PCP is always the first one I call.”

Most respondents seem to feel comfortable about knowing whom to call about health problems, although they don't necessarily agree (PCP vs oncologist). Those with oncologists out of our area may experience more difficulties. Patients with non-oncologic medical conditions may also feel uncertain whether their various specialists are kept current and coordinate their care.

How do local oncologists manage this? Do they continue to provide comprehensive care indefinitely? Do they want to? The following results from the Primary Care Providers portion of our survey address these questions.
Our area includes many practitioners of Complementary/Alternative Medicine (CAM). We asked patients whether they had consulted any CAM practitioners during their cancer journey.

**COMMENTS:**

- “I would have liked to but the cost prohibited that option. Insurance does not cover this kind of treatment.”

- “Friends have suggested traditional stuff like teas that most people take to be healthy but right now I don't think it's a good idea.”

- “Not yet, but I plan on seeing my acupuncturist. I also have a counselor and have seen a chiropractor in the past, but not at present.”

- “I used some traditional healing methods. I'm a firm believer in acupuncture and intend to see my acupuncturist when it's convenient.”
(comments cont’d...)

- “I could not afford alternatives. If I had the money I most likely would try any or all of the below things.” (we had listed some possible CAM practices)
- “What else was there to do?” (answered "No")
- “I would like to. It's been a challenge looking into alternative treatments.”
- “I should've.”
- “Went to Dr. X (who offers nutritional, herbal, and other CAM therapies) once when I was between treatments.”
- “Acupuncture for peripheral neuropathy.”

One third of respondents consulted CAM practitioners, and several more expressed a desire to do so if it were affordable for them. Acupuncture in particular is mentioned. Creating/strengthening partnerships with community CAM practitioners, and possibly, including some treatment options in our program, would benefit patients, and is currently being explored in our Cancer Care Program planning.

- 50% consulted an acupuncturist
- 50% consulted a counselor/stress manager
- 39% consulted a nutritional counselor
- 28% consulted therapeutic massage practitioners
- 22% consulted an herbalist
- 17% consulted a naturopathic doctor
- 11% consulted a traditional or other healer
- 6% consulted a homeopathic practitioner
Since it is important for those providing care to be aware of all the treatments/practices a patient might be employing, we asked patients whether they felt comfortable telling their oncologists/PCP's about the other therapies they were also using.

Twenty four participants responded to this question: 18 answered “yes” and 4 answered “no”, they had not used CAM, but “yes” they would feel comfortable telling their oncologist if they had done so.

Oncologists and PCP’s need to know all the medications-- pharmaceutical, supplements, herbs, etc.--a patient is taking, and the patient needs to feel comfortable discussing this area with them. The chart needs to document all such drugs being used. It can also include the oncologist's advice (pro or con--documenting doesn't necessarily require agreement with the practice, but it seems a good practice in patient care). Some materials from the Integrative Oncology programs at the larger cancer centers (Stanford and UCSF both have them) could help us locally.

It is encouraging that most (almost 80%) of respondents did (or at least felt they could) discuss their CAM with their oncologists/PMD.


- “I discussed it with my oncologist, who disagreed with my taking hemp oil and the mushrooms. She said they would interfere with my chemo, but I did keep doing the mushrooms on the advice of friends and what I read.”

- “He (my oncologist) doesn’t understand Native American (ways). He looks at the clinical, I look at the psychological.”

- “I did tell my oncologist, but did not go into details about the treatment plan that I came back with. I am still reluctant to share all that I am still considering doing and am struggling with this. I don’t want to do alternative treatment without the oncologist knowing what I’m doing.”

- “My primary care doctor is not into the herbal thing.”

- “Oncologist doesn’t approve of herbs etc. as they might impede chemo-untested.”

- “I told them both. THEY weren’t especially comfortable with it.” (respondent consulted a naturopathic doctor)
The timely exchange of information between patients and their local and out-of-area physician(s), and ready access to laboratory and radiologic results used in caring for cancer patients, may present challenges to everyone concerned. We questioned patients about their experiences.

It is encouraging that most patients reported that they found it "easy" to contact their health care providers when they had an important question:

Comments are very positive overall:

COMMENTS:

- “You just pick up the phone and call Dr.X's office (a PCP) Everybody's looking out for me. It's just wonderful. I've been a patient of Dr.X for 24 years.”
- “The local oncologist staff has been extremely helpful, kind, available and compassionate.”
- “They give you their numbers and say call if you have any questions.”
- “Easier with cancer than some other things.”
- “They usually return call same day.”
- “It's hard to talk to them over the phone so I make an appointment.”
Another area where our system performs well is shown in the responses to the question, "When you have an appointment with your cancer care specialist, do/did they have the right documents, such as medical notes, lab results, or X-ray reports, about you?

![Pie chart showing the percentages of responses. The majority are in green, representing 'YES, ALMOST ALWAYS'.]

The responses do highlight some spots for improvement:

**COMMENTS:**

- “Sometimes the lab results took longer than the office expected, so I started going in for the labs a little in advance. It’s great having the lab right there.”

- “The paperwork for my port was delayed a few weeks, which was a big problem. I didn’t get it until after my first infusion.”

- “I make sure it happens. I Fax my results here to UCSF, and I make sure my UCSF PET scans get back to my oncologist here. You have to be pro-active.”

- “They are always very prepared and professional.”

- “Problems with my UCSF providers not getting my lab work to them in time for my appointments.”

Patient Navigators have been useful in this area as well.
Most patients believe that their PCP has been kept up-to-date regarding their cancer treatment:

- 74% Yes, as far as I know
- 2% No
- 24% I don’t know

Only one respondent answered, "No," and her comment was, "Sometimes he got reports back and sometimes not." The majority answered, "Yes," but the Comments suggest some uncertainty about this. The Comments also bring up the question of when, if ever, the patient returns to her PCP after completing cancer therapy. This is an area that perhaps needs further discussion in our Cancer Program.
COMMENTS:

- “I have no idea.”

- “Yes, I switched primary care providers and have Dr.X, (PCP) now. She was very helpful with providing all information about my condition and treatments.”

- “My FNP in Crescent City isn't getting all my results.”

- “It was Dr. X’s (surgeon) practice that each time I saw another doctor (oncologist, radiation specialist, etc.), they were to send a copy of their report to each of my other doctors. So everyone was on the same page.”

- “I fill them in, and they can talk to (oncologist) if they need to.”

- “I don't really have a primary care provider now.”

- “I haven't seen my PCP since this began.”

- “Not always. I had to sometimes take reports to him, or call my specialists to have them send my medical reports to my primary care provider.”

- “I don't see my primary care doc now.”
Almost all patient respondents answered positively when asked whether they were given enough privacy when being examined or treated.

- Yes, always 93%
- Yes, sometimes 5%
- No, often not 2%
Some of their Comments do mention situations where their privacy is compromised, although not every patient finds this to be a problem.

**COMMENTS:**

- “When I have blood draws from my port (on my chest) the door stays open and the curtain is not closed. I can see other patients and people walking by, and they can see me. We are modest people, and this is uncomfortable.”

- “At UCSF there were usually a few others in the room during my exams with the doctor. But once you’ve had a couple of kids and your breasts removed, who cares?”

- “Office yes; infusion centers completely lack privacy. Too many people from the past talk about my health care.”

So while the overall results from this question are very good, a few respondents are quite specific about circumstances where their privacy is not respected. These should be recognized and addressed if possible.
Another area where some patient responses suggest an opportunity for improvement is that of preparations for home care during and following treatment.

When asked, "Did your doctor or nurse give your family or someone close to you all the information they needed to help care for you at home?" the replies were:

- 62% Yes, definitely
- 23% Yes, to some extent
- 4% No, not enough
- 8% No one else involved
- 2% Didn’t need
• “They have made themselves very available. The doctors have even given me their cell phone numbers. That really impressed me!”

• “Limited resources available for providing for care providing services so my husband could sleep at night. We do not qualify for IHS workers.”

• “Instructions were often verbal from the oncologist. The hospital always gave me too much information about care at home and no information about costs!!”

• “I really didn't need help at home from my local treatment. It has not made me sick. I had extensive surgery out of the area and my family was informed of the care I needed.”
When asked, most patients said they did have help at home to assist them during their recovery.

- 70% Yes, all I need
- 11% Yes, but I could use more
- 4% Paid attendant
- 2% No, but would like it
- 13% Don’t need it
- 0 Can’t afford

(We didn't interview caregivers separately -- although often they were present during the interviews-- to assess whether they felt they had enough help and support. This could be an area for further investigation.)
COMMENTS:

- “My son moved in for a while to help my wife take care of me, but I don't need that now.”

- “My roommate and a cousin help me now, but I am applying for IHSS and Disability now for more assistance.”

- “I privately pay for care providers to come in on limited hours to lay me down in the evening on days my husband works.”

- “A social worker came and we got Meals on Wheels, and also my walker and my cane.”

- “The only real assistance I ever needed was when I had to have daily Coumadin shots for blood clots, and my husband gave those to me. Everything else just sort of slid. On the days I felt good, I was able to take care of my normal household responsibilities.”

- “Hard to ask for help, and I could do better at asking for assistance.”

- “My daughter helps me, and I had Home Health also.”
We asked what support services, if any, were used by patients during their cancer treatment. Forty-two (of a total of 55) completed this question, some checking more than one choice, for a total of 84 choices. Results listed in order of how often they were used by those who used any services:

- 57% Support groups (like the Humboldt Community Breast Health Project)
- 31% Psychologist/counselor/stress management
- 24% Look Good Feel Better
- 24% Other ACS services
- 19% Physical therapy
- 17% Housekeeping/meal prep
- 14% Home Health
- 7% Road to Recovery
- 5% Speech therapy
- 2% Occupational therapy
• “Χ, my speech therapist, used Feldenkreis which has really been very helpful. I think you should add her to your list of referrals; Dr. (X ENT) didn't mention her to me.”

• “I didn’t know about Visiting Angels. If I had I would have definitely enlisted their help. I didn’t hear about Road to Recovery or Look Good Feel Better. I didn't seek out a psychologist or counselor because I didn't realize until later that I was very down during treatment and could have benefited from a counselor. I seemed ok during doctor visits but had a lot of internal turmoil.”

• “We stayed at Evergreen lodge and it was very helpful.”

• “We’ve found a personal chef who comes to our home with all her own equipment, and leaves everything spotless.”

• “Evergreen Lodge and (social worker) were super.”

• “I am an Occupational Therapist myself so I am aware of a lot of energy conservation techniques and ways to perform ADL's in a conservative manner.”

• “ANGEL FLIGHT WEST.”

• “Angel flight for transportation to SF.”

• “I get support talking and sharing experiences with other patients during my chemo treatments.”

• “I used both the HBHP and the ACS following completion of my treatments.”

• “Look Good Feel Better was great.”

• “Spiritual support from my church clergy has been important.”

• “I wish I had known about/contacted the Breast Health Project sooner instead of after my surgery.”

• “Hypnotherapy, and lots of time on the computer doing research.”

• “I’m staying at Evergreen Lodge. Church members from Crescent City gave me a ride to Eureka. Today is the first day of my treatment.”
(comments cont’d…)

- “Clinical trial. Physical therapist for back pain, but that is not clearly related to cancer.”
- “Got treatment from physical therapist for peripheral neuropathy (unsuccessful). Dr. X for vague philosophical discussions of death and a referral to hospice evaluation.”

Evergreen Lodge and Angel Flights are very much appreciated by those who’ve used them. And Support Groups including the Humboldt Community Breast Health Project are the most utilized resource, along with other ACS programs. Some respondents’ commented that they would have used resources if they had known about them at the time. Compiling a list of local resources that patients find helpful will prove useful in our Cancer Program, and is being addressed in our Survivorship services.
When we asked patients to choose areas that they would have liked assistance with—areas where a Navigator could help—and gave them a list of possibilities, they often picked several. Of the 42 who responded, a total of 181 options were picked, an average of 4.2 per participant.

Results ranked in order from most popular to least:

- 67% Advice about available community resources & social services
- 65% Help with understanding my diagnostic & treatment options
- 56% Help to ensure needed care info is available & shared with my docs and caregivers
- 49% Someone to "call first" with questions
- 47% Help applying for benefits
- 37% Help coordinating my care
- 33% Help with my insurance/paperwork
- 30% Help with scheduling/tracking appointments
- 14% Help arranging transportation to appointments
- 14% Help arranging care services at home
- 9% Help arranging child- or other care responsibilities
COMMENTS:

- “I think better communication and clarification with patients about their medications is needed. During my treatment I was given 3 different prescriptions for nausea, all from my oncologist, to see which would work best. I didn't know when to start taking them: if I was already nauseated then I couldn't keep it down. I eventually got a suppository from Dr. X which helped, but I felt if had had been given a regimen for when to take the pill with respect to the chemo, it might have prevented the nausea, which was the worst part of the treatment.”

- “I feel that a psycho social evaluation could have been very helpful in my case. I was asked by my doctors if I felt depressed a few times. I answered no because at the time I did not realize that I was depressed. I wasn't sleeping well and was having a fair bit of anxiety which I believe turned into a mild case of PTSD. I thought this was all "normal" for cancer patients due to the severity of the disease. I got excellent care through my surgeon, oncologist and radiologists, (except for a temporary oncologist who told me that I could be terminal.) I think a navigator could have also asked about household issues such as house cleaning, shopping, etc. I had minimal help with these and I believe it could have removed a lot of stress if I had been helped in these areas.”

- “My surgeon was very thorough in discussing my treatment options, but I would have appreciated more information from my oncologist about the pros and cons of the different drugs. Maybe all my doctors are on top of everything that's going on with me (my Crohn's, my arthritis) but they just aren't verbalizing it--I don't know.”

- “Classes or informational workshops, for patients and also for their families.”

- “Handouts given immediately following dx [about] what cancer support groups are available. To be paired with a cancer survivor who could help volunteer to be a breast cancer "buddy", after some initial training, on how to help newly diagnosed patients - helping both the new patient as well validating the knowledge and experience the survivor themselves now have.”

- “Helping a patient come up with questions to ask doctors. Maybe give them a little "kit" with a note book and pen to write questions as well as information on who to call if they need help. It would be good to have one person to call and ask which doctor to take the problem to. For instance I have my oncologist, palliative care doc, primary doc, pain doc. If I have a problem-let’s say an ear ache. Which doc should I call? a navigator could be a person to call and ask.”
(comments cont’d…)

- “I think these (list of possible areas where help is needed) all are very important even if I didn’t need any of them. A lot of people are afraid to ask about their treatment. I use a notebook that comes with me to every appointment, along with a friend or family member who takes notes because you can’t remember it all. However, when I was in the hospital here, I did not care for any of the hospitalists at all! I didn’t like the way they asked their questions (one of them wanted to talk about my jewelry!) and I didn’t feel like they cared for ME. I have many friends who have the same complaint. The nurses had way more information about me.”

- “Information about nutrition and counseling.”

- “Keeping track of all the medications and when to take them was a huge job that I didn’t feel up to during chemo. Thankfully, I was able to get it all arranged prior to starting chemo, and had a dedicated tabletop where I kept it all, along with the directions, so that all I had to do was look at the paperwork and not have to think a lot about what to take when.”

- “Because I have a rarer type of cancer, I was referred to an out of area oncologist -which was the right thing to do. It turns out that the doctor I was referred to was not a fit for me. It may be helpful if Navigators could help facilitate support groups for different types of cancers. Even though this would be a small group for my type, I think the information sharing can be very helpful. For example, I would be very willing to let people know what I learned from my hours of research and also provide internet links to sites that address this form of cancer and provides lists of specialized doctors.”

- “Provide sample recipes for healthy food while undergoing treatment Free classes of yoga. Encourage exercise. I hiked at least 3 miles a day and went to the gym while going through chemo. I stayed strong and had a quick recovery time. Stay out of bed at all possible should be encouraged.”

- “It'd be great for the navigator to be able to help people get "heard" before diagnosis…..Make sure there are not missing pieces falling through the cracks. There were a few problems that occurred before my diagnosis that were frustrating... would have liked someone like a social worker to sit down and go over everything, like what support services or benefits could help me. My daughter called around and was able to get a home health nurse to come out.

- “Everything is located down in Humboldt, and it's expensive to drive down, especially now that the Cancer society stopped with gas money. We really need someone in Crescent City to go to for information about social services and support available.”
(comments cont’d…)

- “They could put people in touch with way to obtain Hemp Salve for peripheral neuropathy and other pains. Also it would be helpful to recommend a foot ointment for peripheral neuropathy (has to be ordered by mail).”

- “Another use for the navigator is to locate the places where the system falls apart: is there adequate communication between specialists, labs, etc.; what key specialists don’t we have up here? It will be useful as a system analytic tool to speed the system response to a patient’s need.”

- “Understanding how to decide between treatment options offered me and what risky procedures to consider.”

- “There are often long delays between appointments with multiple doctors and I wasn’t always sure who I should really be seeing next or how important symptoms might be that I had. Expediting treatment doesn't seem to be a goal of the medical system.”

These comments reinforce prior areas brought up during this survey:

Patients want and need advice about what benefits they might be eligible for, what resources exist that could be of help, and advice about how to keep track of medical appointments, documents, and medication regimens. Respondents also very much would appreciate help in understanding their diagnostic and especially treatment options and side effects.

Patients living out of the Humboldt Bay area have fewer support resources, so must either travel or do without. And not to be forgotten: patients often very much appreciate sharing and learning from another person who has experienced similar challenges. Support groups are especially important, but such groups are concentrated geographically around Eureka and Arcata, and also patients with less common cancers have more difficulty connecting with those sharing their diagnosis. As one participant pointed out, the Cancer Society online has a Cancer Survivors Network with chat rooms and discussion boards, which can facilitate connections (for those with computer access). And cancer survivors often have much they have discovered for themselves that they want to share with fellow patients; facilitating that (perhaps with a file organized by topic) could be done.

Information about nutrition and exercise, during treatment and afterwards, is mentioned. And here as well as in prior survey questions, respondents discuss struggling with the deluge of information involved, and wishing they had some kind of "FAQ" to prompt them to ask important questions when talking with their health care providers.
Our final question was open-ended: "Looking back, knowing what you know now, is there anything you would do differently?"

Forty six respondents answered, ten of them simply said, “no.”

COMMENTS:

- “If I could do something differently I would have sought out counseling. I did not realize at the time the serious impact cancer would make on my life, turning it completely upside down. The mental trauma was indescribable, and now I wish I had turned to a counselor or psychologist for help. I was doing fine on the outside, but there was a lot going on under the surface that I believe could have been helped had the right questions been asked by my medical team. A little bit more probing and in depth questions would have been extremely helpful. Also, my oncologist was an excellent doctor, but there wasn't a lot of emotional support from her. I wish I had spoken up a bit more to my other doctors about this since I saw her weekly through my treatment. Even if they would have referred me to a counselor that would have helped immensely I believe.”

- “I don't think so. I feel I've been allowed to make measured decisions instead of reacting out of fear, and I am glad I took the time to do so.”

- “I would have sought a second opinion when my chronic issues were not resolved/diagnosed within the first year.”

- “Ask more questions. Finding out I had cancer, felt overwhelming, so in the beginning I didn't ask questions often enough. I would set up a system to keep track of records and insurance payments as soon as I got the first bill. I would keep one calendar for all medical appointments, labs and tests, so I could remember what was done when. I discovered that you have to file things by the date of the service, since the doctor has one account number, insurance a different number, and hospitals and labs have their own account numbers. It also helped me, if I made multiple copies of insurance papers, if more than one date was on a page, and checked it off against doctors’ visits, labs or whatever. I also learned to call the billing departments and insurance if something didn't seem to be getting paid. Many times the billing people were happy if I made a small payment, until the insurance paid, which in one case was almost 7 months! Also, keep a record of all calls.”

- “Finding out I’m BRCA-2 positive was a life changer for me, but it didn't happen until after my first recurrence. If I’d had a clue about genetic testing I would have done it sooner. I had a year and a half of remission when I didn't expect it to come back. It's made me rethink the way I look at things, getting my house in order. It seems like in the fall it comes back so I start again on chemo or radiation.”
• "No, I was extremely fortunate to have an early-stage cancer and the best doctors. The only need I had (and didn't even realize it until several monthly after my treatment ended) was what to expect in the coming months and years i.e. depression. Fortunately, the Breast Health Project gives me a place I can ask questions and get answers. But it would have been very helpful to have an ‘exit interview’.”

• "When I found out I had the BRCA gene, my gynecologist (who I was referred to by my primary care physician) ran some tests, but failed to test my CA-125 levels before performing the laparoscopic oophorectomy (to remove my ovaries). During that procedure he discovered I had cancer behind one of my ovaries. He performed a hysterectomy. I subsequently had a second surgery at UCSF when they found another tumor through a CAT scan. That surgery was performed by a gynecologic oncologist.”

• "Ask about what is covered and not covered by insurance. My premiums are the highest at $1500 per month for two people. But, that doesn't help if the treating physician is out of network. My costs that year exceeded $15,000.00!!!”

• "I would stop the chemo sooner, so that I would not have had the cellulitis and neuropathy in my feet.”

• "I wish I had been told about the Breast Health Project while I was being diagnosed and deciding about treatment. I really wish I had understood what the choices meant when my lump was being diagnosed: I would have chosen to have the radiologist do a biopsy at the ultrasound, instead of having the lump removed and then having to go back for another surgery (because the margins were positive after lumpectomy and they hadn't removed any lymph nodes at first).”

• "No. My treatments were successful; I was given sufficient information, and had a good support network.”

• "I would have been more insistent with my primary care doctor. I would not have let so much time go by waiting for further appointments. For instance waiting 3 weeks to get the ultra sound. Then patiently waiting a week for the results, that said it was not likely cancer, and then waiting another few weeks before calling my doctor back to request a specialist. Then waiting two weeks to see her. Then being told the cells looked abnormal after the FNA and that I should do a biopsy, but that there was no rush and I could wait a few months until I finished breastfeeding. Then once finally told I have cancer, the oncologist suggested a route that was unorthodox for the cancer I had (shrinking first). Looking back now, the only change I would make is that I would have left the area sooner. I felt like my tumor was dealt with much more seriously, professionally and with higher quality imagery in Marin. Fortunately I know some people experience that kind of care here. I, for some reason, was not so lucky.”
(comments cont’d…)

- “No. I would research all over again, and continue to do so. I want the most up to date information I can find and know that I need to rely on the internet to keep informed. I know my local oncologist cannot spend the time on a rare cancer and felt the work was up to me – no one else was available.”

- “I would have definitely tried to get more help around the house with housework, rides for my kids, and counseling for myself and my children. Looking back I realize this would have been a great support and would have eased the pressure so to speak. I also realize that I needed an anti-depressant. The chemo caused severe depression, which at the time I thought was "normal." Now I know that most women suffer from depression during chemo. I probably would attend more support groups. At the time I shied away from them because I was scared of hearing about women who had stage 4 breast cancer and were dying.”

- “Yes, I would have sought a third opinion sooner. Stanford doc put me in clinical trial with a dud drug while my cancer grew. He misled me about my options.”

- “I would have sought a second opinion before choosing this treatment for my recurrent cancer. I’ve been in treatment now for 4 months, and finally I called Cancer Care Treatment of America. I didn’t qualify for their program because they don’t accept Medicare, but the representative encouraged me to find a Comprehensive Cancer Center and gave me the names of the 4 closest ones. I chose UC Davis: they were very kind and helpful over the phone, and have arranged for my records to be sent express.”

- “Yes! After the initial tentative diagnosis in July, I’d have pushed for more immediate follow-up. Even the best doctors fail to realize what ‘Let’s watch it and see what develops’ does to a patient.”

- “Of course!”

These patients' and caregivers' honesty, thoughtfulness and generosity with their time in participating in our survey is greatly valued, and will be a major source for developing and improving our Cancer Care Program.
PRIMARY CARE PROVIDERS SURVEY

PURPOSE AND METHODS:

We designed this portion of our Community Needs Assessment to gauge local primary care providers' experience with screening, diagnosis, treatment, and aftercare of their patients with cancer, as well as to learn more about what services are currently available in specific communities. We used existing published references and input from involved community caregivers (see References) to create the questions. Our targeted recipients were primary care providers (MD's, Nurse Practitioners, PA's and alternative/complementary health care clinicians) in our extended service area. With the help of Penny Figas, Executive Director of the Humboldt-Del Norte Medical Society, the Survey* was distributed via SurveyMonkey.com to primary care practitioners, their office managers (to encourage practitioner participation--responses from office managers were not included as separate respondents), and advance practice clinicians. A total of 64 eligible physicians were included; 23 responded, a response rate of 36%. And a total of 63 advance practice clinicians (adult primary care), including one Naturopathic clinician, received our survey, of whom 19 (30%) responded.

Our respondents included practices in Crescent City (Del Norte County), Garberville and Redway (Southern Humboldt County), Willow Creek (eastern Humboldt County), two practices serving the local Native American communities (one in Hoopa, one in Arcata), as well as private and community clinic practices in Arcata, McKinleyville, Fortuna and Eureka. Twenty three respondents work in community health centers, 18 are in private practices, and 2 are in practices serving tribal communities.

<table>
<thead>
<tr>
<th>Provider Respondents by practice type:</th>
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<tbody>
<tr>
<td>Community Health Centers</td>
<td>23</td>
</tr>
<tr>
<td>Private Practices</td>
<td>19</td>
</tr>
<tr>
<td>Tribal Practices</td>
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<table>
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<tr>
<th>Provider Respondents by location:</th>
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<tbody>
<tr>
<td>Eureka</td>
<td>11</td>
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<tr>
<td>Arcata</td>
<td>8</td>
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<tr>
<td>McKinleyville</td>
<td>4</td>
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<tr>
<td>Fortuna</td>
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</tr>
<tr>
<td>Del Norte County</td>
<td>4</td>
</tr>
<tr>
<td>Willow Creek</td>
<td>3</td>
</tr>
<tr>
<td>Tribal (Arcata &amp; Hoopa)</td>
<td>2</td>
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<tr>
<td>Southern Humboldt</td>
<td>6</td>
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</tbody>
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*A copy of the Survey Questions is included in the Appendices.*
PROVIDER SURVEY RESULTS

- Overall, 50% of primary care respondents (MD's & Advance Practice Clinicians) rate local cancer care as adequate, and 30% rate it as excellent. But when analyzed by geographic location, the only "poor" ratings came from Del Norte county (which has no local oncologists).

- One comment from Eureka: "Providers come and go, patients feel vulnerable changing MD's"

- Most of the respondents (45%) see 5 to 20 cancer patients per year, 25% see 20 to 50 cancer patients per year, and a few (in Eureka and Arcata) report seeing more than fifty per year.

A note about the survey methods: The survey was distributed by practice office, so the results won't reflect the proportion of services available by population, i.e., smaller offices' responses count as much as larger ones. Also, due to my SurveyMonkey.com formatting, some respondents' answers were thwarted by a question design that only allowed a given choice to be used once in a grid even if that response applied to more than one of the questions asked. I did send a corrected version, which some respondents returned.
CANCER SCREENING

Seventy per cent of respondents feel secure in making up-to-date cancer screening recommendations to their patients; of these, four commented that they still would appreciate a Community Standard set by the Cancer Program. Thirty one percent answered "No"--they weren't comfortable with their current set of screening guidelines. Thus, forty percent supports having the Cancer Program provide suggested community standards for screening. Practice location had a definite influence on how clinicians responded: all respondents from McKinleyville, SoHum, and tribal practices felt secure in their current screening practices, as did 75% in Arcata & Del Norte. But in Eureka only 64% felt secure, in Willow Creek about the same, and in Fortuna only 17% (1 of 6) felt comfortable, which is significant although not immediately explicable.

COMMENTS:

- "I find no time to discuss all the evidence in our limited office visits. Handouts would be welcome."
- "I am happy with screening. I have a hard time with patients with a (history of cancer) and knowing how to (follow up) best."

When asked about problems encountered when recommending cancer screening, provider respondents rated "patient lack of financial resources" as the most common difficulty, followed by "patient lack of awareness of the importance of screening" and "patient fears about the (screening) procedure."

When analyzed by practice location, Eureka/Arcata/McKinleyville/Fortuna report "lack of awareness..." and lack of financial resources as most common, while in Willow Creek, Del Norte and SoHum, “transportation/accessibility” is the foremost issue, and the tribal/UIHS respondents both cited "patient's difficulty understanding/completing insurance paperwork."

Provider frustration is reflected in such Comments as:

- "..they just don't want to do it even when educated about why and how" (Fortuna)
- "Hmong community WILL NOT let us screen for most cancers" (Del Norte)
- "Poor community, use money for drugs not gas" (Del Norte)
- “Occasionally a referral takes months to process-either because of the UIHS system or because the doctors I refer to for a colonoscopy are booked."
TRACKING ABNORMAL SCREENING RESULTS OR INITIAL DIAGNOSIS OF CANCER

In trying to discover where patients could "get lost" in the cancer care continuum, we inquired whether patients ever failed to return for results following a suspicious finding on a cancer screening. Overall 60% of respondents reported this occurred "rarely" or "never". When analyzed by practice location, Eureka/Arcata/McKinleyville and Willow Creek respondents mostly (92%) report their patients fall into these (rare or never) categories. But in Fortuna, Del Norte, SoHum and tribal practices, the majority (73%) report this "sometimes" happens.

<table>
<thead>
<tr>
<th>Practice Location</th>
<th>OFTEN</th>
<th>SOMETIMES</th>
<th>RARELY</th>
<th>NEVER</th>
</tr>
</thead>
<tbody>
<tr>
<td>EUREKA</td>
<td></td>
<td></td>
<td>82%</td>
<td>18%</td>
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<tr>
<td>ARCATA</td>
<td>12%</td>
<td>13%</td>
<td>75%</td>
<td>--</td>
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<tr>
<td>MCKINLEYVILLE</td>
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<td>--</td>
<td>100%</td>
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<tr>
<td>FORTUNA</td>
<td>--</td>
<td>67%</td>
<td>33%</td>
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<tr>
<td>DEL NORTE</td>
<td>--</td>
<td>100%</td>
<td>--</td>
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<tr>
<td>SO HUM</td>
<td>--</td>
<td>40%</td>
<td>40%</td>
<td>20%</td>
</tr>
<tr>
<td>WILLOW CREEK</td>
<td>--</td>
<td>--</td>
<td>100%</td>
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<tr>
<td>TRIBAL</td>
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<td>100%</td>
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</table>

Likewise, when asked whether patients ever failed to return after a diagnosis of cancer was made, 77% of respondents said this happens “Rarely” or “Never” (and 23% said “Sometimes”). Again, those reporting "Sometimes" were more common in Fortuna, Del Norte, SoHum, Willow Creek & Tribal practices. (I do note that this question could have been interpreted by respondents that the patient failed to return AFTER BEING REFERRED FOR TREATMENT following the initial diagnosis of cancer, but there is still a difference between practice locations.) This suggests that patients from areas outside Eureka/Arcata/McKinleyville are more likely to "drop out" at the time of screening, and that patient tracking is especially important in these areas.
We then asked whether practitioners followed up/"tracked" these "lost" patients. Combining the responses "No" and "Yes, but inconsistently", a significant number of respondents (43%) in all localities gave these responses: 45% in Eureka, 38% in Arcata, 25% in McKinleyville, 66% in Fortuna; 67% in SoHum, 33% in Willow Creek, and 50% in tribal/UIHS practices. Interestingly, all respondents in Del Norte said "Yes," i.e., they tracked. Again, the respondents could have interpreted this as patients, having been given results, THEREAFTER not returning to their PCP's, but in any case the number of respondents who report tracking these patients inconsistently is of concern.

<table>
<thead>
<tr>
<th></th>
<th>YES, BUT INCONSISTENTLY</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>EUREKA</td>
<td>36%</td>
<td>9%</td>
</tr>
<tr>
<td>ARCATA</td>
<td>38%</td>
<td>--</td>
</tr>
<tr>
<td>MCKINLEYVILLE</td>
<td>25%</td>
<td>--</td>
</tr>
<tr>
<td>FORTUNA</td>
<td>50%</td>
<td>17%</td>
</tr>
<tr>
<td>DEL NORTE</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>SO HUM</td>
<td>17%</td>
<td>50%</td>
</tr>
<tr>
<td>WILLOW CREEK</td>
<td>--</td>
<td>33%</td>
</tr>
<tr>
<td>TRIBAL</td>
<td>50%</td>
<td>--</td>
</tr>
</tbody>
</table>

COMMENTS:

- “They start their treatment & seem not to be told to contact me. The MD NEVER calls.”
- “They seem to fall into a referral cycle. I receive notes after decisions have been made without my input.”

For those patients who were tracked, we then asked practitioners what reasons the patients give for not returning. Overall, “Financial issues” were most commonly cited by respondents in all areas. In Eureka/Arcata/McK/Fortuna, the next most common reason was “Finding a second opinion outside of our area”, and then “Fear”. In Del Norte/SoHum/Willow Creek & tribal practices (the latter 2 with only 1 respondent each for this question), after "Financial issues" respondents reported "other life problems" and “transportation issues”, then “Fear”, and only then “Finding a second opinion”.

This suggests that in areas where medical and other resources are scarce, the choice of a second opinion is a relatively rare one, compared to the other challenges patients face in their lives, including transportation for follow-up on suspicious findings.
INSURANCE STATUS OF PATIENTS

Thirty five providers gave estimates of the insurance status of their patient population overall. All of those who reported 75-100% of their patients covered by private insurance or MediCare were located in Eureka/Arcata/McKinleyville (6) or in Fortuna (1); another 7 (5 from Eureka/Arcata/McK, 1 from Fortuna, 1 Del Norte) estimated 50-75% of their patients had this coverage.

For providers estimating less than 50% of their patients had private or MediCare coverage, the majority were from outlying areas. These figures suggest that the Eureka/Arcata/McKinleyville area has a higher proportion of patients with private insurance or Medicare, compared with communities further away from this combined population center, and that Del Norte in particular has a very low rate of private insurance.

PROVIDER ESTIMATES OF INSURANCE OVERALL (% based on # of respondents)

(data on following page)
<table>
<thead>
<tr>
<th>AREA</th>
<th># RESPONDENTS</th>
<th>TOTAL RESPONDENTS</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>75-100%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EUR/ARC/MCK</td>
<td>6</td>
<td>23</td>
<td>26%</td>
</tr>
<tr>
<td>FORTUNA</td>
<td>1</td>
<td>6</td>
<td>17%</td>
</tr>
<tr>
<td><strong>50-75%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EUR/ARC/MCK</td>
<td>5</td>
<td>23</td>
<td>22%</td>
</tr>
<tr>
<td>DEL NORTE</td>
<td>1</td>
<td>4</td>
<td>25%</td>
</tr>
<tr>
<td>FORTUNA</td>
<td>1</td>
<td>6</td>
<td>17%</td>
</tr>
<tr>
<td><strong>10-50%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EUR/ARC/MCK</td>
<td>6</td>
<td>23</td>
<td>26%</td>
</tr>
<tr>
<td>DEL NORTE</td>
<td>1</td>
<td>4</td>
<td>25%</td>
</tr>
<tr>
<td>SO HUM</td>
<td>5</td>
<td>6</td>
<td>83%</td>
</tr>
<tr>
<td>WILLOW CREEK</td>
<td>2</td>
<td>3</td>
<td>67%</td>
</tr>
<tr>
<td>FORTUNA</td>
<td>4</td>
<td>6</td>
<td>67%</td>
</tr>
<tr>
<td>TRIBAL</td>
<td>1</td>
<td>2</td>
<td>50%</td>
</tr>
<tr>
<td><strong>&lt;10%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DEL NORTE</td>
<td>2</td>
<td>4</td>
<td>50%</td>
</tr>
<tr>
<td><strong>DON'T KNOW</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DEL NORTE</td>
<td>1</td>
<td>4</td>
<td>25%</td>
</tr>
</tbody>
</table>

**TOTAL ANSWERS: 36**
This disparity (more privately-insured patients in the Humboldt Bay region) is reflected in reciprocal fashion by looking at the providers' estimates of their patients covered by publicly-funded insurance programs.

Twenty-six percent of respondents from Eureka/Arcata/McKinleyville estimate that less than 10% of their patients have public insurance coverage, while 50% from Del Norte reported this.

PROVIDER ESTIMATES OF PUBLIC INSURANCE (% based on # of respondents)

(data on following page)
<table>
<thead>
<tr>
<th>AREA</th>
<th># RESPONDENDS</th>
<th>TOTAL RESPONDENTS</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>75-100%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EUR/ARC/MCK</td>
<td>1</td>
<td>23</td>
<td>4%</td>
</tr>
<tr>
<td><strong>50-75%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EUR/ARC/MCK</td>
<td>2</td>
<td>23</td>
<td>9%</td>
</tr>
<tr>
<td>DEL NORTE</td>
<td>2</td>
<td>4</td>
<td>50%</td>
</tr>
<tr>
<td>SO HUM</td>
<td>1</td>
<td>6</td>
<td>17%</td>
</tr>
<tr>
<td>WILLOW CREEK</td>
<td>1</td>
<td>3</td>
<td>33%</td>
</tr>
<tr>
<td>FORTUNA</td>
<td>1</td>
<td>6</td>
<td>17%</td>
</tr>
<tr>
<td><strong>10-50%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EUR/ARC/MCK</td>
<td>6</td>
<td>23</td>
<td>26%</td>
</tr>
<tr>
<td>DEL NORTE</td>
<td>1</td>
<td>4</td>
<td>25%</td>
</tr>
<tr>
<td>SO HUM</td>
<td>3</td>
<td>6</td>
<td>50%</td>
</tr>
<tr>
<td>WILLOW CREEK</td>
<td>2</td>
<td>3</td>
<td>67%</td>
</tr>
<tr>
<td>FORTUNA</td>
<td>3</td>
<td>6</td>
<td>50%</td>
</tr>
<tr>
<td>TRIBAL</td>
<td>1</td>
<td>2</td>
<td>50%</td>
</tr>
<tr>
<td><strong>&lt;10%</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EUR/ARC/MCK</td>
<td>6</td>
<td>23</td>
<td>26%</td>
</tr>
<tr>
<td>FORTUNA</td>
<td>1</td>
<td>6</td>
<td>17%</td>
</tr>
<tr>
<td><strong>DON'T KNOW</strong></td>
<td></td>
<td></td>
<td>11%</td>
</tr>
<tr>
<td>ALL LOCATIONS</td>
<td>5</td>
<td>44</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL ANSWERS: 38**
UNDOCUMENTED RESIDENTS

California has a significant number of unauthorized immigrants (estimated at 2.6 million in 2010, 7% of the state's population). In 2009, Humboldt County had an estimated 2000 unauthorized immigrants (1.6% of the population)*. Del Norte's total was combined with 3 other low-population nearby counties, but it was estimated to include 1% unauthorized/undocumented.

Locally, the counties of our service area all belong to CMSP, the County Medical Services Program consortium, which offers enrollment-based coverage for those who qualify. All of our service-area counties offer CMSP coverage only to those immigrants with legal documentation.

Most of the respondents (43) to our Provider survey who answered the question, "What percent of patients in your practice are undocumented residents?" reported "less than 10 percent." But 3 respondents, one each in Del Norte, Fortuna, and Southern Humboldt, estimated 10-50% of their patients to be undocumented, and one practitioner, from Del Norte, reported 50-75%. This same practitioner estimated 10-50% of his/her cancer patients were in this group.

So, while our service-area population currently contains relatively few unauthorized immigrants, this number is expected to rise, and our current medical coverage provisions do not extend to these potential patients.

*"Unauthorized Immigrants in California," Public Policy Institute of California, 2011, p.16
AVAILABLE SUPPORT SERVICES WITHIN MEDICAL PRACTICES

❖ Seventy-five percent of Eureka/Arcata/McKinleyville respondents say they have in-office staff to assist cancer patients with insurance and benefits applications and paperwork. Fortuna is close with 66%, but Southern Humboldt respondents report only 40% of their offices offer such help, and Willow Creek reports only 33% with such.

Perhaps surprisingly, 75% of Del Norte responders offer such services, all of them centered on assisting in the application for public medical assistance programs. In contrast, the majority (81%) of in-office benefits help in Eureka/Arcata/McKinleyville supports coordinating private insurance benefits. Southern Humboldt respondents say that those offices that do offer these services primarily help in applying for public medical assistance, and less commonly help with pre-authorization.

COMMENTS:

❖ "We could use more help with this - only minimal services and staff" (Del Norte)

❖ "Really don't have specially trained personnel. We all try to help them the best we can but it is not in a standard way at all." (Southern Humboldt)

❖ “We have case workers and MA's knowledgeable about CDP options.” (HODC Eureka)

❖ The majority (58%) of respondents say their offices offer no in-house supportive services (other than finance-related, like those mentioned above) for cancer patients. Within this figure, though, are local differences: all (2) of the tribal offices have psychological/stress management, and one has nutritional support. In Arcata & McKinleyville, more than 80% reported some available in-office services. In contrast, none of the Fortuna respondents report any services available through their offices and in Eureka 70% say they have none.

Of respondents who said they had some services available, the most common was stress/psychological management (offered in at least one office everywhere except Fortuna). Only 2 respondents said their offices had peer support groups, and the only respondents who had cancer library materials available were in Eureka and Arcata (3 of 22).

We didn’t design this survey to differentiate between larger group practices (whether private or "community") and smaller offices, but responses such as these likely reflect the larger ancillary staff often found in bigger practices in more populous areas.
REFERRAL PROCESS FOR CANCER PATIENTS

REFERRING LOCALLY:

- When asked, "If you and your patient decide to begin cancer treatment locally, how difficult is it for you to refer your patient for cancer treatment?" over half (59%) of respondents stated they had occasional difficulty in referring their cancer patients in our area.

Provider Difficulty Arranging Referrals for Cancer Treatment

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, difficulty arranging referral for cancer treatment</td>
<td>30%</td>
</tr>
<tr>
<td>Occasionally have difficulty</td>
<td>59%</td>
</tr>
<tr>
<td>About half the time difficulty</td>
<td>5%</td>
</tr>
<tr>
<td>Frequently have difficulty</td>
<td>0%</td>
</tr>
<tr>
<td>Almost always have difficulty</td>
<td>7%</td>
</tr>
</tbody>
</table>
Most of the respondents who reported "No difficulties" referring patients for treatment locally are located in Eureka/Arcata/McKinleyville (10); the others were in Southern Humboldt (2) and Willow Creek (1). On the other end of the spectrum, Del Norte reported having a problem "Almost always" 67% of the time (2 of 3 respondents). Most everyone else reported "Occasionally" (26) or "About half the time" (2) having a problem. This includes all Fortuna respondents, 4/6 responses from SoHum, and all the tribal practice replies. Willow Creek was divided: “No problem” (1 of 3), “Occasional problem” (1 of 3), and "About half of the time there's a problem" (1 of 3).

COMMENTS:

- "When the primary is unknown, getting oncologists interested is somewhat difficult." (McKinleyville)
- “Transportation is THE BIGGEST ISSUE. There is NO local treatment." (Del Norte)
- "We have no local cancer services." (Del Norte)
- From a respondent who reported “No problem”: "I have grateful for this" (sic) (Southern Humboldt)
- “I have no problems probably due to my relationships with oncology providers.” (Eureka)
When asked, "What are the main difficulties you encounter in arranging timely treatment for your patients with cancer locally?" the most common was "The amount of time it takes to get an appointment," followed by "Lack of enough cancer specialists."

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>#</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of Specialists</td>
<td>21 of 83</td>
<td>55%</td>
</tr>
<tr>
<td>Amount of Time to Get Appointment</td>
<td>28</td>
<td>74%</td>
</tr>
<tr>
<td>Coordination of Care</td>
<td>16</td>
<td>42%</td>
</tr>
<tr>
<td>Distance for Patient to/from Providers</td>
<td>18</td>
<td>47%</td>
</tr>
</tbody>
</table>
As would be expected, respondents whose practices are more distant from the oncologists find the distance the patient must travel to and from treatment to be a major problem: all the respondents from Del Norte, Willow Creek and the tribal practices cited distance as a difficulty, as did 4 out of 5 respondents from Southern Humboldt. In comparison only 7% (2 of 23) respondents from Eureka/Arcata/McKinleyville called this a problem, and 50% (3 of 6) from Fortuna did.

Overall, the most common problem cited was the amount of time it takes to get an appointment (73% overall, with respondents from every area citing this at least 50% of the time). Lack of enough cancer specialists was also cited in at least 50% of the responses from all areas, including Eureka/Arcata/McKinleyville, except in Southern Humboldt (1 of 5 respondents=20%).

This is an area we can hope to improve upon.
The majority of respondents refer at least some cancer patients out of our area for treatment, although 6 of 44 (14%) say they don’t do so. The respondents who reported not referring out were in Eureka (1), Arcata (1), McKinleyville (1), Willow Creek (2) and SoHum (1), i.e. scattered. Of course no practitioners in Del Norte don’t refer.

Most respondents report referring <10% of their patients out of area (100% of Fortuna, SoHum, Willow Creek and tribal). Oddly, 2 of 4 respondents in Del Norte said they referred <10% of their cancer patients out of area, while the other 2 Del Norte respondents report 75-100% referral out of area. Other than these 2 respondents in Del Norte county, only the Eureka/Arcata/Mck area included respondents reporting an out-of-area referral rate of >10%. This primarily came from Eureka respondents, 55% of who refer out of area more than 10% of the time. Arcata had 1 respondent (out of 7, 14%) who had a 10-50% referral rate. McKinleyville had none.

This could suggest that cancer patients from outlying areas are less likely to be referred for clinical trials (since at present there are no such trials up here), although it may also reflect that while the primary practitioner refers to a local oncologist, the patient may ultimately referred (by the oncologist) out of the area.
When asked for reasons for out-of-area cancer referrals, "Patient preference" is the chief reason reported by respondents, cited 72% of the time. Next most common was "Rare cancer type," at 57%. "Availability of clinical trials" and of "More therapeutic options" were cited by 46%. "Lack of confidence in local oncology services" was cited by only 10%. In the "Other" category, reasons mentioned had to do with treatment options for specific cancer sites not locally available, such as orthopedic, gynecologic, "neuro" and stem cell transplants.

**REASONS FOR REFERRING OUT OF AREA**

When analyzed by practice location, Arcata had a majority of respondents (75%) citing "The availability of clinical trials", and 75% also citing "more diagnostic modalities available" as reasons they refer out. No other practice location had more than 50% of respondents mentioning these. Also, perhaps of interest, 3 of the 4 total respondents citing "lack of confidence in local services" were from Eureka; the fourth was from Fortuna, but the respondent added, "Patient lack of confidence not ours".

**COMMENTS:**

Eureka:

- "Difficulty coordinating care, difficulty getting patients seen locally in a timely fashion"

Del Norte:

- "All patients get referred out. Southern Oregon Oncology is great about getting our patients right in"
FOLLOWING UP ON CANCER PATIENT REFERRALS

Since we wanted to search out stages in the cancer care continuum where patients might become lost or delay treatment, we inquired whether practitioners tracked their referred patients "to make sure the referral is completed and the patient has been seen."

Most respondents (76%) say their office follows up after referring a cancer patient, to verify that the patient has been seen. This is done primarily by phone, sometimes by a designated staff member; by asking the patient at follow-up visits, and/or by reviewing consulting notes. Looked at by area, most respondents in Eureka, Arcata, Del Norte and all of McKinleyville and Southern Humboldt respondents say they track. But only 50% of Fortuna, Willow Creek and tribal respondents say their practices do so. This is, potentially, a place where cancer patients could "fall through the cracks," and where a Patient Navigator could help.

When asked whether they receive progress reports from LOCAL oncology consultants, the majority (80%) of respondents "always" or "usually" did so. But 17% reported only "sometimes" or "not very often" receiving reports: one each from Eureka, Fortuna and Del Norte. One Arcata practitioner added, "local progress reports are not very helpful."

Regarding OUT OF AREA consultants, 73% reported "always" or "usually" getting progress reports and 27% said they "sometimes" or "not very often" did. For unknown reasons, 83% of Arcata respondents said they only "sometimes" or "not very often" got such reports.

Most respondents reported that they remain primarily responsible for non-cancer-related health care while their patients are undergoing cancer therapy. Close to half say their practice "almost always" remains responsible, and another 34% say they "usually" do. Nine percent of respondents say the consultant usually assumes this responsibility. This may not necessarily be by choice. A comment from Fortuna: "We have no choice. Oncology refuses to talk to them and tells their staff to call the PMD."

(See graph on following page)
THE CANCER TREATMENT EXPERIENCE

CHALLENGES FACED BY PATIENTS & AVAILABILITY OF SUPPORT SERVICES
AS REPORTED BY PROVIDERS

As a group, practitioners cited the "Adverse effects of treatment" as the most common reason patients fail to complete the prescribed course. No one said this was not an issue. Other common problems cited were lack of financial resources, lack of supportive services to help at home, a preference for alternative/complementary therapy, and transportation/accessibility issues. Twenty percent of respondents were not sure whether their patients' cultural beliefs led to their discontinuing treatment, while 25% felt this was not an issue.

**AVG. PROVIDER RATING OF FACTORS THAT INTERFERING WITH COMPLETION OF TREATMENT (SCALE 1-4)**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adverse effects</td>
<td>2.29</td>
</tr>
<tr>
<td>Access/Transport</td>
<td>2.69</td>
</tr>
<tr>
<td>Oncology Appointment Availability</td>
<td>2.98</td>
</tr>
<tr>
<td>Difficulty w/ Ins. Paperwork</td>
<td>3.15</td>
</tr>
<tr>
<td>Lack of Resources</td>
<td>2.40</td>
</tr>
<tr>
<td>Lack of Support</td>
<td>2.56</td>
</tr>
<tr>
<td>Life Issues</td>
<td>2.68</td>
</tr>
<tr>
<td>Cultural</td>
<td>3.27</td>
</tr>
<tr>
<td>Alternative Therapy</td>
<td>2.73</td>
</tr>
<tr>
<td>Patient Concerns</td>
<td>2.73</td>
</tr>
</tbody>
</table>
When broken down by geographic area, there were some differences in how practitioners responded:

- Concerns about treatment effectiveness were most commonly cited in Arcata (89% said it was "frequently" or "sometimes" an issue) and also in Fortuna and McKinleyville, but less often reported in Eureka (30%) or Southern Humboldt (20%).

- Transportation/accessibility of care is, as expected, more of a problem in Del Norte and tribal practices, but even in Eureka, 30% of respondents said it was frequently or sometimes an issue.

- Lack of (patient) financial resources was cited by respondents in every area, but was felt to be a more common issue for patients in Del Norte, SoHum, Willow Creek, Fortuna and tribal practices.

- Availability of oncology appointments was less of a problem (10%) in Eureka, and not a problem at all according to the McKinleyville respondents, while Fortuna practitioners surprisingly reported it was frequently or sometimes an issue 86% of the time. Del Norte & tribal respondents reported this was frequently or sometimes a problem 100% of the time.

- Lacks of supportive services to help at home was a common problem in Willow Creek, tribal practices, Fortuna, and Del Norte, but even in Eureka and Arcata, close to half of practitioners report this as a problem for their patients.

- Regarding other issues in a patient's life having higher immediate priority than cancer treatment, Willow Creek, Del Norte, SoHum and tribal practices all had 100% of respondents saying this was a “frequent” or “sometimes” issue. This is in contrast to Eureka (20%), or McKinleyville (33%); Arcata & Fortuna fall in between.

- Patient preference for alternative/complementary treatment was most reported by Southern Humboldt practitioners (50% of respondents cited this as a frequent reason their patients failed to complete treatment, the most in any area).
The need for home health services (home IV's, wound care, occupational or physical therapy, etc.) is another need patients with cancer may experience. Twenty-eight percent of practitioner respondents were uncertain how many of their patients had such needs, but of those who offered an estimate, close to half (44%) thought 10-50% of their patients did.

**Provider Estimates of Patients with Home Health Needs**

![Graph showing provider estimates]

Overall, 63% of respondents said that all or most of these home health services were readily available. But there was a definite disparity between practice locations. No one from Arcata, McKinleyville or Fortuna said that these services were few or virtually not available. In Eureka, one respondent reported "few" available services; no one in Eureka said none were available. All the practitioners from Arcata & McKinleyville, 80% from Eureka, and 67% from Fortuna said that services were all or mostly readily available.

The response pattern was almost reversed in Del Norte, Willow Creek, SoHum and tribal practices: none of these respondents reported "all services are readily available" and only 2 (14%) said "most services are..."
COMMENTS:

- "Patient resources are more limiting than are medical resources." (Eureka)

- "Poor physician-physician communication fragments care" (Arcata)

- "NO HOME HEALTH in So. Humboldt!!!!!" (Southern Humboldt)

- "No home health or hospice care available in Willow Creek area, and our practice still does some home visits to try to allow for some end of life care if patient opts for that, but if there are no support persons in patient's life, the care can be overwhelming for the clinic to provide." (Willow Creek)
Homemaker services (help with meals, personal care, housekeeping etc.) is another area of need for some cancer patients. When asked whether homemaker services are available, only 14% of respondents answered simply, "yes." Most (60%) answered, "yes, but only for those with insurance or funds to pay for them." 16% said these services weren't available, and 9% weren't sure.

When broken down by area, those reporting "no services available" included Arcata as well as Del Norte, SoHum, Willow Creek and tribal practitioners. No respondents in Eureka, McKinleyville or Fortuna reported no available homemaker services.

**PROVIDERS’ ESTIMATED AVAILABILITY OF HOMEMAKER SERVICES**
ARRANGING SERVICES FOR CANCER PATIENTS

Providers were asked if there were any services they had a difficult time arranging for their patients. Seventy-two percent of respondents overall reported "yes," there are difficulties arranging services for their cancer patients. Unsurprisingly, all (100%) of the practitioners in Del Norte, Willow Creek and tribal practices answered "yes," as did 67% from Southern Humboldt. Comments from everywhere mentioned need for home health & in-home services, and some respondents added additional area of challenge.

 COMMENTS:  

Eureka:

• "Transportation to UCSF"

• "It's never easy to play intern for a specialist who demands that we (the PCP's) get studies done that they may want. This is more of a concern for out of the area specialists, however"

• "Home care for patients unable to afford it, social work services"
(comments cont’d…)

Fortuna:

- "Takes time to arrange visits - seems to depend on the diagnosis involved. People who live in more remote areas are difficult to find support for."
- "PET CT, getting the patients in with Oncology soon"
- "Appointment with oncology, treatment plans, follow ups, home supports"
- "Completing paperwork medical assistants are already very busy and at times referral are not done"

Del Norte:

- "If a person is not homebound, i.e. go to church, they can't qualify for our home health. we have no hospice available."
- "Case management, transportation, hospice"
- "Hospice"

Willow Creek:

- "Home care and wound care are hard to cover, due to lack of trained people, and distance to coast is overwhelming for people needing frequent visits, as well as tiring for patients needing the care"
HOSPICE SERVICES

Hospice service availability is very much dependent upon patient/practitioner location. Overall, 81% of respondents reported hospice was available to their patients; in Eureka, Arcata, McKinleyville and Fortuna, 100% of respondents said so. But there's no hospice available in Del Norte (although one DN practitioner wrote, "But we do have nurses who assume that function just not called Hospice as no doctor overseeing"), and only limited services elsewhere.

OVERALL HOSPICE AVAILABILITY

- "Actually we have our local Hospice, but it is not funded by MediCare."
  (Southern Humboldt)

- "No the official Medicare Hospice benefit, though we have provided home visits when family wish to remain at home, but it can spread us quite thin and overwhelming on medical providers." (Willow Creek)
Even where hospice care is available; it may not become involved in a timely fashion. Overall, only 35% of respondents replied that "Hospice usually becomes involved when the patient is expected to live only 6 months," which is the interval often advised (of course depending on when the patient decides to forgo further possible curative treatment). Another 20% reported hospice involvement typically at 3 months. Twelve percent responded "one month," and 9% reported "only a matter of days or weeks." Twenty-four percent responded "Not sure."

**TIMING OF HOSPICE INVOLVEMENT IN PATIENT CARE**

Some practitioners clearly feel that referrals for hospice care are not being made early enough in the final months of a patient's illness.

**COMMENTS:**

- "Oncology (in general) waits WAY too long to refer to Hospice."

- "The patients usually aren't directly told by Oncology how bad it is. There are told the odds and left to the patient to continue treatment. Sometimes it's a relief for them to hear me say "It's time to stop." Then I get Hospice but I feel we're cutting it too close. There must be a better way to get the patients enrolled sooner. It isn't a Hospice problem, but an Oncology/PMD problem."
Another question asked was "Have you presented a cancer case to your hospital's Tumor Board?" Most (64%) of the respondents said they had not presented a case: no one from Del Norte, SoHum or tribal practices had done so. Distance (from office to hospital) undoubtedly accounts for much of this, but even in Eureka, one practitioner wrote, "While it would be worthwhile, it would be a practice and a financial hardship to do so...given the realities of outpatient medicine these days." Teleconferencing could possibly facilitate more practitioners' participation, as suggested by one respondent.
PRACTITIONER SUGGESTIONS

Finally, the practitioners were asked to add any additional suggestions to this part of the Community Needs Assessment. Ten of them responded:

• "The Willow Creek area is unique in being longer distance from either hospital, and patients’ needs can be disjointed due to a multitude of issues, including distance, transportation, financial issues and lack of support systems or infrastructure for advanced care options, both for patient and the medical providers that seek to provide care to those patients."

• "I would love more information on recommended f/u for various cancers (for the primary provider once oncology is no longer involved) OR a place to go to for researching an individual pt's history and what would be recommended. Cost of colonoscopy can be prohibitive, but now we're offering free FIT testing, which is good."

• "I have had a few issues with specialists that perform a screening evaluation (i.e. colonoscopy) and then expect the primary care provider to review the results with the patient. I have had to call the hospital to get the path results because they were not sent to me and the specialist did not bother to make sure that I did get the results. Some of the specialists feel that it is our responsibility to review the results with the patient. I happen to think it is theirs to review with the patient. Additionally, some of the specialists who perform the screening procedure think their job is done after they inform the pt right after the procedure when the pt is still amnestic and groggy."

• "I am very interested in this process and would like to be of assistance if needed, thanks!" (from Redway)

• "I think that doing this survey is a great idea, but I suspect that my responses may not be typical due to my status as a very senior primary care provider who at one time was the "chemotherapist of last resort" in the Arcata area."

• "I think we all need to be more respectful of those people who want to do little or nothing for their advanced cancer. The above questions did not talk much about palliative care, e.g."

• "The PMD should be the patients "home". Major decisions regards the patient's. Management should involve the PMD."

• "Communications are difficult with EMR challenges, obtaining referrals etc. I wish Drs. would use HIPaa compliant DocBooks for referrals in all specialties."
• "Need more availability of social workers to sort out home care, stress, and financial issues"

• "It saddens me that these days a referral to hospice is essentially a loss of the patient from my practice and my care. It used to be that I remained the physician of record. That is no longer the case, so patients whom I've known for years suddenly are lost to me - unless, of course, I want to maintain a purely social contact. I do understand why hospice does this... at least I think I understand... but it is not, in my opinion, and for me and my patients, an ideal situation."
CONCLUSION

The conclusions drawn from this Needs Assessment document are outlined in the Executive Summary. Our Cancer Care Service Area is very large, the oncology services are concentrated in Eureka and we are understaffed both in primary care providers and in oncologists. Our population has a high rate of poverty, public medical insurance coverage, and cancer risk/incidence. Cancer patient support services are also concentrated around Humboldt Bay, leaving many patients and their caregivers lacking resources near their homes. Primary care providers, especially in outlying areas, also experience this dearth of supportive services, and the communication and referral processes from health care provider to provider are other areas of concern. Patients are not always “tracked” and can “get lost” or, at least, experience delays in cancer care. Both patients and providers express their wish for our help at many stages of the cancer experience, as they state so eloquently in their Comments. It is our hope that this Needs Assessment will help our Patient Navigation program, and our Cancer Care Program overall, to achieve the vision we all share.
REFERENCES


- UCLA Center for Health Policy Research, CHIS (California Health Interview Survey) http://healthpolicy.ucla.edu/chis/Pages/default.aspx

- California Center for Rural Policy (CCRP) http://www.humboldt.edu/ccrp/


- "Patient Navigation in Cancer Care: Guiding Patients to Quality Outcomes"™
- Pfizer Inc 2008 http://www.patientnavigation.com/home?LMenulId=100
- National Cancer Institute "Family Caregivers in Cancer (PDQ) 8/01/2013 http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/patient/page1
- State Cancer Profiles, National Cancer Institute http://statecancerprofiles.cancer.gov/index.html
- California Cancer Registry, California Department of Public Health, http://www.ccrcal.org
- Harold P. Freeman Patient Navigation Institute http://www.hpfreemanpni.org/
- California Department of Finance Demographic Reports P-1 Summary Population Projections http://www.dof.ca.gov/research/demographic/reports/projections/P-1/
- Stephen Hunt Taplin and Anne Brown Rodgers "Toward Improving the Quality of Cancer Care: Addressing the Interfaces of Primary and Oncology-Related Subspecialty Care"


PATIENT & CAREGIVERS SURVEY, 2013-14

SURVEY COVER LETTER:

Hello,

My name is Diane Korsower, and I'm a local retired physician volunteering with the Cancer Care Program at St. Joseph's Hospital. Dr. Ellen Mahoney is in the process of creating a Cancer Patient Navigation service here, and I'm helping her & other committee members design such a program. Patient Navigators can help patients and their families make their way through the fragmented maze of doctors’ offices, clinics, hospitals, outpatient centers, payment systems, support organizations and other components of the health care system, offering help in accessing care; coordinating services; facilitating communication among patients, family members, and health care providers; helping with paperwork and transportation arrangements, and many other possible roles.

The first step in creating a Navigation service is to take stock of how cancer care locally is working now: a Community Needs Assessment. People with cancer, and their families and caregivers, are at the center of this Needs Assessment (other parts address primary care providers, cancer treatment specialists, and support providers and organizations). So this Patient/Caregiver Questionnaire is the real heart of the process. We’re interested in the experiences of people with cancer here in our Humboldt/Del Norte community, with the goal of identifying both what’s working well already and what needs improvement.

I designed this survey intending to offer it to people with cancer individually, one-on-one, with me jotting down their responses in an interactive way. But I’ve found that many people prefer to complete it privately at their leisure, so it is also available for you to complete online at: https://www.surveymonkey.com/s/YRZNJJV

I want to emphasize that all responses will be strictly confidential--you needn’t include your name or other identifying information if you choose--and while the results will be analyzed and shared with the cancer care committee, your individual remarks will not be linked in any way to your identity.

On behalf of the Cancer Care Program at St. Joseph Hospital, and at Redwood Memorial Hospital, I want to thank you for taking the time to contribute to this project. Your experiences, your suggestions, the wisdom you’ve gained during your illness, are invaluable and will be used to help local people with cancer currently and in the future.

Sincerely,
Diane Korsower M.D.
## SURVEY QUESTIONS

### DEMOGRAPHICS

1. **WHO ARE YOU?**
   - Initials:
   - City/Town:
   - Zip:

2. **WHAT IS YOUR AGE?**

3. **WHAT IS YOUR GENDER?**
   - Female
   - Male

4. **ARE YOU A PERSON WITH CANCER YOURSELF?**
   - Yes
   - No, I'm a family member of a person with cancer
   - No, I'm a friend/caregiver of a person with cancer

5. **DO YOU SHARE YOUR HOME WITH ANYONE ELSE?**
   - I live alone and independently
   - I live alone with assistance from caregivers
   - I live with my spouse/life partner only
   - I live with more than one family member or friend
   - I live with roommates
   - I live in a care facility
   - I have no fixed place to live

Other living arrangements (please specify):
6. **WHAT IS THE HIGHEST LEVEL OF SCHOOL THAT YOU HAVE COMPLETED?**

- [ ] Primary school
- [ ] Some high school, but no diploma
- [ ] High school diploma (or GED)
- [ ] Some college, but no degree
- [ ] 2-year college degree
- [ ] 4-year college degree
- [ ] Graduate-level degree

Comments?

7. **IS ENGLISH YOUR FIRST LANGUAGE?**

- [ ] Yes
- [ ] No

Comments?

8. **LOCATION OF YOUR PRIMARY CARE PROVIDER, IF ANY?**

- City/Town:
  - How far is it from your home?
  - How do you get there?

9. **WHAT IS THE DISTANCE TO YOUR CANCER CARE SPECIALIST(S)?**

- How do you get there?
10. ARE YOU RECEIVING ANY BENEFITS (SOCIAL SECURITY DISABILITY INSURANCE, SSI ETC.) AS A RESULT OF YOUR CANCER?

☐ Yes
☐ No

Comments?

11. WHAT KIND OF CANCER DO YOU HAVE?

12. HOW LONG AGO WERE YOU TOLD YOU HAVE CANCER?

☐ Less than three months ago
☐ Three to six months ago
☐ Six months to a year ago
☐ One to five years ago
☐ More than five years ago
☐ I have had more than one cancer

Comments?

13. HAVE YOU RECEIVED CARE FOR YOUR CANCER OUTSIDE OF OUR (HUMBOLDT/DEL NORTE) AREA?

☐ No
☐ Yes

If so, where?

14. WHAT HEALTH INSURANCE DID YOU HAVE AT THE TIME YOU WERE FIRST DIAGNOSED? YOU CAN CHECK MORE THAN ONE RESPONSE:

☐ Private insurance
☐ MediCare
☐ Supplemental insurance
☐ MediCal, Path2Health or other public program
☐ No insurance

Other (please specify):
15. HOW LONG WAS IT FROM THE TIME YOU FIRST THOUGHT SOMETHING MIGHT BE WRONG WITH YOU UNTIL YOU FIRST SAW A HEALTH CARE PROVIDER ABOUT IT?

☐ Less than a month
☐ Less than 3 months
☐ 3-6 months
☐ More than 6 months
☐ Don’t know/can’t remember

Comments?

16. IF YOU DELAYED SEEKING CARE, WHY?:

(You can choose more than one answer)

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<thead>
<tr>
<th>MOST IMPORTANT REASON</th>
<th>IMPORTANT</th>
<th>SOMEWHAT IMPORTANT</th>
<th>OF MINOR IMPORTANCE</th>
<th>N/A</th>
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<tr>
<td>Financial reasons: lack of insurance/high deductible/couldn’t afford</td>
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<td>Didn’t have a primary care provider</td>
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<td>Lack of transportation to care</td>
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<td>Child care of other caregiver responsibilities</td>
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<td>Work responsibilities</td>
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<td>Afraid</td>
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<td>Other life problems were more important</td>
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<td>Don’t trust doctors</td>
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Comments?
17. BEFORE YOU WERE TOLD YOU HAD CANCER, HOW MANY TIMES DID YOU SEE YOUR PRIMARY HEALTH CARE PROVIDER ABOUT THE HEALTH PROBLEM CAUSED BY THE CANCER?

☐ None (for example, you were diagnosed during an emergency room visit)
☐ Once
☐ Twice
☐ Three
☐ More than three times
☐ Don't know/can't say

Comments?

18. HOW MANY DOCTORS DID YOU CONSULT WITH BEFORE RECEIVING YOUR DIAGNOSIS?

☐ One
☐ Two
☐ More than two

Comments?

19. IF YOUR CANCER WAS DIAGNOSED BY A SURGICAL PROCEDURE (BIOPSY, FINE NEEDLE ASPIRATION) OR SCAN (XRAY, CT, MRI), HOW LONG DID IT TAKE FOR YOU TO BE INFORMED OF THE RESULTS?

☐ One or two days
☐ Less than a week
☐ One to two weeks
☐ More than two weeks

Comments?

20. DID YOU UNDERSTAND THE EXPLANATION OF WHAT WAS WRONG WITH YOU?

☐ Yes, I completely understood it
☐ Yes, I understood some of it
☐ No, I didn't understand it at the time
☐ Can't remember

Comments?
21. WHAT STAGE WAS YOUR CANCER WHEN IT WAS INITIALLY DIAGNOSED?

☐ Stage I

☐ Stage II

☐ Stage III

☐ Stage IV

☐ Don't know/can't recall

Comments?

22. DID YOUR PRIMARY CARE PROVIDER OFFER WRITTEN INFORMATION ABOUT YOUR CANCER, OR SUGGEST OTHER SOURCES OF INFORMATION?

☐ Yes, I received all the information I wanted

☐ Yes, I received some information, but I wanted more

☐ No

☐ I did not want any more information

Comments?
MAKING A DECISION ABOUT CANCER TREATMENT

23. AFTER YOU LEARNED YOU HAD CANCER, HOW LONG DID IT TAKE FOR YOU TO SEE A CANCER CARE SPECIALIST TO DISCUSS TREATMENT CHOICES?

- [ ] One to three days
- [ ] Three to seven days
- [ ] One to two weeks
- [ ] Two to four weeks
- [ ] More than a month

If it took longer than two weeks, why? Any comments?

24. WHAT SOURCE(S) OF INFORMATION HAVE YOU USED IN DECIDING WHAT TREATMENT YOU CHOSE?

<table>
<thead>
<tr>
<th>Source(s) of Information</th>
<th>VERY IMPORTANT</th>
<th>IMPORTANT</th>
<th>SOMEWWHAT IMPORTANT</th>
<th>NOT VERY IMPORTANT</th>
<th>N/A</th>
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<tbody>
<tr>
<td>I relied on my oncologist’s recommendations</td>
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<tr>
<td>Alternative/complementary medicine recommendations</td>
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<td>Friends and family</td>
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<td>American Cancer Society</td>
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<td>National Cancer Institute</td>
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<td>Online blogs or personal testimonials</td>
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<td>Other online sources</td>
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<tr>
<td>Local support organizations</td>
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</table>

Other sources or comments?
25. HOW DO YOU FEEL ABOUT THE INFORMATION AVAILABLE TO YOU WHEN YOU DECIDED ABOUT YOUR CANCER TREATMENT?

- I wanted more information than was available to me
- I am comfortable with the amount of information available to me
- I felt there was too much information available to me
- I would have liked help in finding more information or in making sense of it

Comments?

26. DID YOU RECEIVE SUFFICIENT INFORMATION ABOUT THE ADVANTAGES AND DISADVANTAGES OF DIFFERENT TREATMENTS, SO YOU COULD MAKE A PROPER CHOICE?

- Yes
- Yes, but I needed to search for it myself
- No I would have liked help finding this information

Comments?

27. BEFORE BEGINNING YOUR CANCER TREATMENT, DID YOU CONSIDER DIFFERENT POSSIBLE SOURCES OF CARE?

- Yes, I had a consultation/second opinion out of our area
- Yes, I consulted complementary/alternative practitioner(s)
- Yes, I wanted to, but my circumstances (insurance/finances, job or other responsibilities, travel distance required, etc.) did not allow this
- No

Comments?
28. WHAT FACTORS INFLUENCED YOUR DECISION ABOUT WHICH TREATMENT TO CHOOSE? IF YOU CAN, PLEASE INDICATE HOW IMPORTANT THEY WERE IN MAKING YOUR DECISION.

<table>
<thead>
<tr>
<th>THE MOST IMPORTANT REASON</th>
<th>VERY IMPORTANT</th>
<th>IMPORTANT</th>
<th>SOMEWHAT IMPORTANT</th>
<th>NOT VERY IMPORTANT</th>
<th>NOT AT ALL IMPORTANT</th>
<th>N/A</th>
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<tr>
<td>Financial/insurance coverage to pay for the costs</td>
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<td>Transportation to and from treatment</td>
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<td>Trust that the treatment would be successful</td>
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<td>Trust in my doctors</td>
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<tr>
<td>Worry about the side effects of treatment</td>
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<td>Advice from my friends /family</td>
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<td>Responsibilities as a care provider for children or spouse</td>
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<td>Need to keep my job</td>
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<tr>
<td>Other issues in my life were more important</td>
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Comments?
29. DID YOU SPEAK WITH SOMEONE, LIKE A SOCIAL WORKER, NURSE, OR OTHER SOURCE OF INFORMATION, ABOUT WHAT RESOURCES ARE AVAILABLE TO HELP AND SUPPORT YOU DURING YOUR ILLNESS?

☐ Yes, at my doctor's office
☐ Yes, at the oncologist's office
☐ Yes, at a support organization outside of my doctor's office
☐ No, but I would have wanted to do so
☐ No, I didn't want to do so

Comments?

(continues on next page)
THE CANCER TREATMENT EXPERIENCE

30. AFTER YOUR FIRST CONSULTATION VISIT WITH YOUR CANCER CARE SPECIALIST, HOW LONG DID IT TAKE TO BEGIN YOUR TREATMENT?

☐ One to three days
☐ Three to seven days
☐ One to two weeks
☐ More than a month

If it took longer than two weeks, why? Comments?

31. ARE/WERE YOU INVOLVED AS MUCH AS YOU WANT(ED) TO BE IN DECISIONS ABOUT YOUR CARE AND TREATMENT?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, but I would have liked to be more involved
☐ Not sure/can’t remember

Other (please specify):
32. WHAT PROBLEMS ARE/HAVE YOU EXPERIENCED DURING YOUR CANCER TREATMENT?

Choose all that apply to you, and if possible rate how challenging they have been.

<table>
<thead>
<tr>
<th></th>
<th>MOST</th>
<th>VERY</th>
<th>IMPORTANT</th>
<th>SOMewhat</th>
<th>NOT VERY</th>
<th>N/A</th>
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<tr>
<td>The side effects of the treatments</td>
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<tr>
<td>Transportation to treatments/doctor’s appointments</td>
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<td>Transportation to shop, see friends, religious services</td>
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<td>Concerns about other people's learning of/reactions to my illness</td>
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<td>My need to keep my job</td>
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<td>Keeping track of/ organizing my appointments</td>
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<td>Keeping track of/ organizing my insurance and related bills</td>
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<td>Keeping track of/ organizing my medications, refills, etc.</td>
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<td>Keeping track of/ organizing my medical records and test results</td>
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<td>Shopping and preparing meals</td>
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<td>Keeping up with housework, laundry, etc.</td>
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<td>My emotional state, my feelings about this experience</td>
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<td>Worries about my family</td>
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<td>Spiritual concerns</td>
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<td>Uncertainty about my future</td>
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Comments?
33. WERE YOU GIVEN A TREATMENT PLAN SUMMARY AND INFORMATION ABOUT ITS POTENTIAL IMPACT ON YOUR LIFE?

☐ Yes, I received enough information and my questions were answered  
☐ Yes, I received some information, but I still had some questions that were not addressed  
☐ No, I had many questions that were not addressed  
☐ No, but I didn't want any more information

Other (please specify):

34. DO YOU HAVE A CLEAR IDEA OF WHICH HEALTH CARE PROVIDER IS "IN CHARGE" OF YOUR CARE, WHO TO CALL IF YOU HAVE A PROBLEM?

☐ Yes, definitely  
☐ Yes, to some extent  
☐ No, and this is sometimes a problem  
☐ No, but this hasn't caused any problems  
☐ Not really sure

Comments?

35. DURING YOUR CANCER TREATMENTS, HAVE YOU ALSO CONSULTED ALTERNATIVE/COMPLEMENTARY CARE PROVIDERS?

☐ Yes  
☐ No

Comments?

36. IF YES, WHAT KIND?

(Select all that apply)

☐ Herbalist  
☐ Acupuncturist  
☐ Therapeutic massage  
☐ Counselors/stress management  
☐ Nutritional counselor  
☐ Other/traditional healer  
☐ Naturopathic doctor  
☐ Homeopathic doctor  
☐ Other (please specify):
37. IF YES, DO/DID YOU FEEL COMFORTABLE TELLING YOUR ONCOLOGIST/PRIMARY CARE PROVIDER ABOUT THE OTHER CARE PROVIDERS YOU SEE?

☐ Yes
☐ No

Comments?

38. WHEN YOU HAVE IMPORTANT QUESTIONS ABOUT YOUR CONDITION OR CARE, HOW EASY IS IT FOR YOU TO CONTACT YOUR CARE PROVIDERS?

☐ Easy
☐ Sometimes easy, sometimes difficult
☐ Difficult
☐ I have not tried to contact him/her

Comments?

39. WHEN YOU HAVE AN APPOINTMENT WITH YOUR CANCER CARE SPECIALIST, DO/DID THEY HAVE THE RIGHT DOCUMENTS, SUCH AS MEDICAL NOTES, LAB TEST RESULTS, OR X-RAY REPORTS ABOUT YOU?

☐ Yes, almost always
☐ Yes, some of the time
☐ Often they did not

Comments?

40. AS FAR AS YOU KNOW, IS/WAS YOUR PRIMARY CARE PROVIDER GIVEN ENOUGH INFORMATION ABOUT YOUR CONDITION AND TREATMENTS FROM YOUR CANCER CARE SPECIALIST?

☐ Yes
☐ No
☐ Don’t know

Comments?
41. ARE YOU GIVEN ENOUGH PRIVACY WHEN BEING EXAMINED OR TREATED?

☐ Yes, always
☐ Yes, sometimes
☐ No, often not

Comments?

42. DID YOUR DOCTOR OR NURSE GIVE YOUR FAMILY OR SOMEONE CLOSE TO YOU ALL THE INFORMATION THEY NEEDED TO HELP CARE FOR YOU AT HOME?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, not enough
☐ No family or friends were involved
☐ My family or friends did not want or need information

Comments?

43. DO YOU HAVE HELP AT HOME TO ASSIST YOU DURING YOUR RECOVERY?

☐ Yes, my family/friends give all the help I need
☐ Yes, family/friends give some help, but I could use more
☐ I have help from a paid attendant(s)
☐ I have no help at home, but would appreciate this
☐ I don't require any assistance
☐ I can't afford home assistance

Comments?
44. WHAT SUPPORT SERVICES, IF ANY, HAVE YOU USED DURING YOUR CANCER TREATMENT?
CHOOSE ALL THAT APPLY:

☐ Home health
☐ Housekeeping/meal preparation help (Visiting Angels or private arrangements)
☐ Road to Recovery
☐ Look Good Feel Better
☐ Other American Cancer Society services
☐ Support groups like the Humboldt Breast Health Project
☐ Psychologist/counselor/stress management
☐ Physical therapy
☐ Occupational therapy
☐ Speech therapy

Other (please specify):

Comments?
45. AS WE’VE MENTIONED, THIS HOSPITAL IS PLANNING TO CREATE A PATIENT NAVIGATION SERVICE FOR PEOPLE WITH CANCER IN OUR COMMUNITIES. WHAT, IF ANY, POSSIBLE AREAS WOULD YOU HAVE LIKED HELP WITH DURING YOUR ILLNESS?

(Choose as many as you wish.)

☐ Help with understanding my diagnosis and treatment options
☐ Help with scheduling and keeping track of my appointments
☐ Help arranging transportation to my appointments
☐ Help arranging childcare or other care responsibilities
☐ Help in applying for any benefits I might be eligible for
☐ Help arranging care services at my home
☐ Help with my insurance/billing paperwork
☐ Someone to 'call first' when I have a question or problem
☐ Advice about what community resources and social services are available
☐ Help to ensuring that all the necessary information about my treatment is available and communicated to my doctors and caregivers
☐ Help coordinating my care

Any other suggestions for how a navigator could help?
46. LOOKING BACK, KNOWING WHAT YOU KNOW NOW, IS THERE ANYTHING YOU WOULD DO DIFFERENTLY?

Thank you for your valuable time and help with this survey. We will use your replies and suggestions as we create our Cancer Patient Navigation service here, and your experiences will contribute to improving care for patients now and in the future.
The Cancer Care Program of the St. Joseph Health System-Humboldt County is creating a Cancer Patient Navigation program. Patient Navigation assists cancer patients, their families and caregivers, from pre-diagnosis through all phases of the cancer experience. By facilitating timely access to appropriate medical and psychosocial services, Patient Navigation services can help save lives and overcome barriers to accessing care.

Cancer patient navigation can and should take on different forms in different communities. A crucial first step in implementing this program and new accreditation requirements of the American College of Surgeons (ACOG) Commission on Cancer is a Community Needs Assessment. Our goals are to identify barriers to accessing care and to identify gaps in services. We also want to know what’s working well here now.

We will be surveying those in our community whose lives and work involve cancer:

- Patients and their caregivers/families
- Community primary health care providers
- Oncology/palliative care specialists
- Other supportive service providers

These questions are for Community Primary Health Care Providers. We thank you for your time and thoughts. Please include your own comments and suggestions. Some questions can best be answered by health care providers themselves; other questions are best answered by office staff. Please share these questions within your organization to complete the survey with the most accuracy. Your help is vital to creating a Patient Navigation program that fits our particular community needs, and which ensures that we’re providing the right care, at the right time, by the right person.

Who will see your information? Only Drs. Diane Korsower and Ellen Mahoney, and the data analyst, will see these forms. All public documents will not include any identifiable data. This site is secure and the information you submit is encrypted and password protected.

There are 35 questions which we believe can be answered in 15 minutes or less. We hope to complete this part of our Needs Assessment by July 8, 2013.

Diane Korsower M.D., Volunteer, Cancer Care Program
Ellen Mahoney M.D., Medical Director, Cancer Care Program
SURVEY QUESTIONS

1. NAME OF PRACTICE

2. NAME & SPECIALTY/TITLE OF PROVIDER ANSWERING QUESTIONS

(3. NAME OF OTHER PERSON(S) ANSWERING QUESTIONS)

4. WHERE IS YOUR PRACTICE LOCATED?

- Eureka
- Arcata
- McKinleyville
- Fortuna
- Del Norte County
- Southern Humboldt
- Willow Creek area
- Tribal/UIHS practice

5. APPROXIMATELY HOW MANY PATIENTS WITH CANCER DO YOU SEE IN A YEAR?
(Regardless of whether a new case or on-going and regardless of whether you made the initial diagnosis or it was made elsewhere.)

- We never see patients with cancer at our practice
- 5 or fewer cancer patients per year
- 5 to 20 cancer patients per year
- 20 to 50 cancer patients per year
- Greater than 50 cancer patients per year
6. WHAT IS YOUR PERCEPTION OF THE CARE FOR CANCER PATIENTS AVAILABLE IN OUR COMMUNITY NOW?

- BEST POSSIBLE care, state of the art.
- EXCELLENT overall, very good for all but a small subset of patients.
- ADEQUATE but there are a few areas that need to be improved.
- POOR QUALITY such that I advise most of my patients to seek treatment and opinions outside of the area.
- VARIABLE depending on factors such as type of cancer or patient's life circumstances.
- DON'T KNOW/unsure.
- Other (please specify):

7. DO YOU FEEL SECURE IN MAKING UP-TO-DATE CANCER SCREENING RECOMMENDATIONS TO YOUR PATIENTS?

- YES I have a set of screening guidelines for primary care that I am comfortable with.
- NO I find the multitude of differing screening guidelines a problem. I would appreciate having a community standard set by the Cancer Program.
- Other (please specify):
8. PLEASE RATE THE DIFFICULTIES YOU’VE ENCOUNTERED WHEN RECOMMENDING YOUR PATIENTS UNDERGO ROUTINE CANCER SCREENING

(e.g., mammography, colonoscopy, etc.) According to national guidelines.

<table>
<thead>
<tr>
<th>FREQUENT ISSUE</th>
<th>SOMETIMES</th>
<th>RARELY</th>
<th>NO PROBLEMS NOTED</th>
<th>DON’T KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient lack of awareness of the importance of screening</td>
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<td>Patient misperceptions about screening effectiveness</td>
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<td>Patient fears about the screening procedure (for example, colonoscopy)</td>
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<td>Patient accessibility transportation issues</td>
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<tr>
<td>Patient’s difficulty understanding/completing paperwork for insurance</td>
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<td>Patient’s lack of financial resources</td>
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<tr>
<td>Other patient life issues (e.g., homelessness, legal problems) have higher immediate priority</td>
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</tbody>
</table>

Other or comments?
9. HOW OFTEN DO YOUR PATIENTS FAIL TO RETURN TO YOUR PRACTICE AS SCHEDULED AFTER SUSPICIOUS FINDINGS ARE DISCOVERED BY CANCER SCREENING EXAMINATIONS (MAMMOGRAMS, BLOOD WORK, FOB ETC.)?

- Never
- Rarely (less than 10%)
- Sometimes (11% to 25%)
- Often (26-50%)
- Very Frequently (over 50%)

Comments?

10. HOW OFTEN DO YOUR PATIENTS FAIL TO RETURN TO YOUR PRACTICE AS SCHEDULED AFTER AN INITIAL DIAGNOSIS OF CANCER HAS BEEN MADE?

- Never
- Rarely (less than 10%)
- Sometimes (11% to 25%)
- Often (26-50%)
- Very Frequently (over 50%)

Comments?

11. DOES YOUR PRACTICE FOLLOW UP (TRACK) THESE PATIENTS?

- YES we telephone the patient
- YES we send a registered letter
- YES we send a secure email
- YES but inconsistently
- NO
12. IF "YES", WHAT ARE THE REASONS PATIENTS GIVE FOR NOT RETURNING?

<table>
<thead>
<tr>
<th>Reason</th>
<th>COMMONLY CITED</th>
<th>SOMETIMES CITED</th>
<th>RARELY CITED</th>
<th>NEVER CITED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child-or other care issues</td>
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<tr>
<td>Seeking a second opinion locally</td>
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<tr>
<td>Fear</td>
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<tr>
<td>Didn't understand the significance of the finding</td>
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<tr>
<td>Seeking a second opinion outside our area</td>
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<tr>
<td>Financial issues (for example, lack of insurance, can't miss work, high deductible)</td>
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<td></td>
<td></td>
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<tr>
<td>Problems understanding/completing paperwork for insurance</td>
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<td></td>
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<tr>
<td>Language barriers</td>
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<tr>
<td>Other life issues (e.g., homelessness, legal problems) have higher immediate priority</td>
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<tr>
<td>Transportation difficulties</td>
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<tr>
<td>Cultural belief system/differences in health care</td>
<td></td>
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</tbody>
</table>

Other (please specify):
13. WHAT PERCENTAGE OF PATIENTS IN YOUR PRACTICE HAVE PRIVATE INSURANCE OR MEDICARE?

<table>
<thead>
<tr>
<th>Patients in your practice overall</th>
<th>Patients with cancer in your practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 10%</td>
<td></td>
</tr>
<tr>
<td>10-50%</td>
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<tr>
<td>50-75%</td>
<td></td>
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<tr>
<td>75-100%</td>
<td></td>
</tr>
<tr>
<td>Don't know/unsure</td>
<td></td>
</tr>
</tbody>
</table>

Comments?

14. WHAT PERCENT OF YOUR PATIENTS QUALIFY FOR MEDI/CALPATH2HEALTH/CMSP?

<table>
<thead>
<tr>
<th>Patients in your practice overall</th>
<th>Patients with cancer in your practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 10%</td>
<td></td>
</tr>
<tr>
<td>10-50%</td>
<td></td>
</tr>
<tr>
<td>50-75%</td>
<td></td>
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<tr>
<td>75-100%</td>
<td></td>
</tr>
<tr>
<td>Don't know/unsure</td>
<td></td>
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</tbody>
</table>

Comments?
15. WHAT PERCENT OF PATIENTS IN YOUR PRACTICE ARE UNDOCUMENTED RESIDENTS?

<table>
<thead>
<tr>
<th>Patients in your practice overall</th>
<th>Patients in your practice with cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 10%</td>
<td></td>
</tr>
<tr>
<td>10-50%</td>
<td></td>
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<tr>
<td>50-75%</td>
<td></td>
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<tr>
<td>75-100%</td>
<td></td>
</tr>
<tr>
<td>Don’t know/unsure</td>
<td></td>
</tr>
</tbody>
</table>

Comments?

16. CANCER PATIENTS OFTEN HAVE FINANCIAL CONCERNS ABOUT THEIR CARE COSTS, INSURANCE COVERAGE, LOSS OF EMPLOYMENT AND INCOME, APPLYING FOR SOCIAL SECURITY/DISABILITY, OR PAYING FOR THEIR HOUSING AND TRANSPORTATION. DO YOU HAVE TRAINED STAFF IN YOUR OFFICE TO ASSIST THEM?

☐ Yes
☐ No

17. WHAT SERVICES DO THEY PROVIDE?

☐ Help coordinating private insurance coverage
☐ Help applying for public medical assistance programs
☐ Help applying for Social Security/Disability or other benefits
☐ Obtaining Pre-Authorization for diagnostic studies? Chemotherapy? Other drugs or services?
☐ Other services (please specify):
18. DOES YOUR OFFICE OFFER SUPPORTIVE PROGRAMS FOR CANCER PATIENTS, SUCH AS:

☐ Support groups led by peers?
☐ A library of materials for cancer patients?
☐ Dietician/nutritional services?
☐ Psychological/stress management support?
☐ NONE within our office

Other (please specify):

19. IF YOU AND YOUR PATIENT DECIDE TO BEGIN CANCER TREATMENT LOCALLY, HOW DIFFICULT IS IT FOR YOU TO REFER YOUR PATIENT FOR CANCER TREATMENT?

☐ We have NO difficulty arranging timely treatment for cancer patients
☐ OCCASIONALLY we have difficulty arranging timely treatment for cancer patients
☐ ABOUT HALF THE TIME we have difficulty arranging timely treatment for cancer patients
☐ FREQUENTLY we have difficulty arranging timely treatment for cancer patients
☐ ALMOST ALWAYS we have difficulty arranging timely treatment for cancer patients

Comments?

20. WHAT ARE THE MAIN DIFFICULTIES YOU ENCOUNTER IN ARRANGING TIMELY TREATMENT FOR YOUR PATIENTS WITH CANCER LOCALLY?

(Please check all that apply)

☐ Lack of enough cancer specialists
☐ Amount of time it takes to get an appointment
☐ Coordination of care between your office & the specialist
☐ Distance for patient to and from treatment location

Other (please specify):
21. HAVE YOU REFERRED PATIENTS WITH CANCER FOR CARE OUTSIDE OF OUR AREA?
☐ Yes
☐ No

22. IF YES, APPROXIMATELY WHAT PERCENTAGE OF YOUR PATIENTS DO YOU REFER OUT?
☐ Less than 10%
☐ 10-50%
☐ 50-75%
☐ 75-100%

23. IF YES, WHY?
(Please check all that apply)
☐ Patient preference
☐ Availability of clinical trials
☐ More diagnostic modalities available
☐ More therapeutic options available
☐ Rare cancer type
☐ Lack of confidence in local oncology services
Other (please specify)

24. ONCE YOU HAVE REFERRED A PATIENT WITH CANCER, DOES YOUR OFFICE FOLLOW UP TO MAKE SURE THE REFERRAL IS COMPLETED AND THE PATIENT HAS BEEN SEEN?
☐ Yes
☐ No
Other or comments?

25. IF YES, HOW?
26. WHEN YOU REFER A PATIENT FOR CANCER TREATMENT, DO YOU RECEIVE CURRENT PROGRESS REPORTS AND CARE PLANS FROM THE CANCER SPECIALIST?

<table>
<thead>
<tr>
<th>From local consultant</th>
<th>From consultants out of our area</th>
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</thead>
<tbody>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>Usually</td>
<td></td>
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<tr>
<td>Sometimes</td>
<td></td>
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<tr>
<td>Not very often</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
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</table>

Comments?
27. WHAT FACTORS, IF ANY, INTERFERE WITH YOUR CANCER PATIENTS' COMPLETION OF THEIR TREATMENT PLAN?

<table>
<thead>
<tr>
<th>Factor</th>
<th>Frequent Issue</th>
<th>Sometimes an Issue</th>
<th>Occasionally an Issue</th>
<th>Not an Issue</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient concerns about treatment effectiveness</td>
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<tr>
<td>Adverse effects of the treatment</td>
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<td>Patient accessibility/transportation issues</td>
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<td>Availability of oncology appointments</td>
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<td>Patient's difficulty understanding/completing paperwork for insurance</td>
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<td>Patient's lack of financial resources</td>
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<tr>
<td>Lack of supportive services to help at home</td>
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<tr>
<td>Other patient life issues (e.g., homelessness, legal problems) have higher immediate priority</td>
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<tr>
<td>Patient's cultural beliefs</td>
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<tr>
<td>Patient prefers alternative/complementary therapy</td>
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<tr>
<td>Other (please specify)</td>
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</tbody>
</table>
28. ONCE A PATIENT WITH CANCER HAS BEEN REFERRED FOR TREATMENT, WHICH MEDICAL PRACTICE IS RESPONSIBLE FOR THE PATIENT’S ONGOING NON-CANCER-RELATED CARE?

- Our practice almost always remains responsible for non-cancer care.
- Our practice usually remains responsible, but the consultants sometimes assume this role.
- Non-cancer-related care is shared between our office and the consultants.
- The consultant(s) usually assumes primary responsibility while the patient is receiving cancer treatment.
- The arrangement varies depending on the circumstances.

Comments?

29. PATIENTS WITH CANCER OFTEN REQUIRE HOME HEALTH SERVICES, SUCH AS WOUND CARE, HOME OXYGEN NEEDS, HOME IV FLUIDS OR ANTIBIOTICS, BLOOD DRAWS, PHYSICAL THERAPY, OCCUPATIONAL THERAPY, OR MEDICATION AND SYMPTOM MANAGEMENT. APPROXIMATELY WHAT PERCENT OF YOUR CANCER PATIENTS REQUIRE SUCH HOME HEALTH SERVICES?

- Less than 10%
- 10-50%
- 50-75%
- 75-100%
- Don't know/not sure

30. IN YOUR PRACTICE AREA, TO WHAT EXTENT ARE THESE SERVICES READILY AVAILABLE FOR YOUR PATIENTS WITH CANCER?

- All services are readily available
- Most services are readily available
- Some services are readily available
- A few services are readily available
- Virtually none of these services are readily available

Comments?
31. PATIENTS WITH CANCER MAY NEED HELP AT HOME WITH MEAL PREPARATION, PERSONAL CARE, OR HOMEMAKER ASSISTANCE. ARE THESE SERVICES AVAILABLE TO YOU PATIENTS?

☐ YES
☐ YES but only for those with insurance or funds to pay for them
☐ NOT AVAILABLE in my area
☐ Don’t know/not sure

32. ARE THERE ANY SERVICES THAT YOU FIND DIFFICULTY IN ARRANGING?

☐ Yes
☐ No

Please explain:

33. IS HOSPICE CARE AVAILABLE TO YOUR CANCER PATIENTS?

☐ Yes
☐ No

Comments?
34. IF HOSPICE SERVICES ARE AVAILABLE FOR YOUR PATIENTS, ARE THEY UTILIZED AT AN APPROPRIATE TIME DURING THE COURSE OF THE CANCER PATIENT’S ILLNESS?

☐ Hospice services usually become involved close to when the patient is expected to live only six months

☐ Hospice services usually become involved close to when the patient is expected to live only three months

☐ Hospice services usually become involved close to when the patient is expected to live only one month

☐ Hospice services usually become involved close to when the patient is expected to live only a matter of days or weeks

☐ Not sure

Comments?

35. HAVE YOU PRESENTED A CANCER CASE TO YOUR HOSPITAL’S TUMOR BOARD?

☐ Yes

☐ No

Comments?
36. PLEASE TELL US ANYTHING ELSE THAT WOULD BE HELPFUL TO THIS NEEDS ASSESSMENT.

Thank you very much for your assistance.