



PATIENT PERSPECTIVES

on ovarian cancer

September 2013



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The Ovarian Cancer National Alliance is a powerful voice for everyone touched by ovarian cancer. We connect survivors, women at risk, caregivers and health providers with the information and resources they need. We ensure that ovarian cancer is a priority for lawmakers and agencies in Washington, DC, and throughout the country. We help our community raise their voices on behalf of every life that has been affected by this disease.

Washington, DC —When a report was published this spring showing that fewer than half of women with ovarian cancer receive standard-of-care treatment, everyone in our community took notice. Studies have shown that this treatment can prolong women’s lives—a critical concern given that this is the deadliest gynecologic cancer and the fifth leading cause of cancer deaths among women.

We wanted to hear directly from our community about their experiences with ovarian cancer treatment. What barriers were preventing women from receiving the best treatment? How could the Ovarian Cancer National Alliance improve women’s access to care? After several conversations with Dr. Robert Bristow, lead author of the study that inspired our questions, we partnered with Inspire on a survey that explored ovarian cancer diagnosis and treatment from the patient perspective. We were thrilled to receive more than 1,000 responses to our survey.

Some of the answers reported here are encouraging. We saw signs that women are being diagnosed more rapidly than in 2007, when we conducted a similar survey. Most of the women who responded to our study did report receiving standard-of-care treatment, likely because they represent a population with better-than-average access to health care.

There is still a great deal we need to learn about which women are not receiving the best treatment for ovarian cancer, why that happens and how it affects their survival and quality of life. We hope this survey will be a stepping stone for further research that can lead to better outcomes for every woman diagnosed with ovarian cancer.



Calaneet Balas

CEO, Ovarian Cancer National Alliance

“Improving access to specialty-trained providers (gynecologic oncologists) and high-volume healthcare delivery centers has been identified as an important mechanism by which the survival outcome for women with ovarian cancer can be improved. The Ovarian Cancer National Alliance survey offers valuable insight into population characteristics that predict timely access and receipt of appropriate care. These data also provide a necessary benchmark from which to further investigate barriers to receiving standard treatment for ethnic minorities and women of low socioeconomic status.”

Robert Bristow, MD, MBA

Director, Gynecologic Oncology Services, UC Irvine Medical Center

Patient Perspectives:

Introduction

Ovarian cancer is the deadliest gynecologic cancer and the fifth leading cause of cancer-related deaths among women.¹ Research has shown that being treated by a gynecologic oncologist and receiving standard-of-care treatment (currently, surgery followed by six rounds of chemotherapy) increases a woman's chances of survival, yet a study released this March found that most women with ovarian cancer are not receiving such treatment.² Dr. Robert Bristow and his colleagues examined the records of 13,321 patients treated for epithelial ovarian cancer between 1999 and 2006. They found that just 37.2% received care that adhered to the National Comprehensive Cancer Network (NCCN) guidelines.

At the Ovarian Cancer National Alliance, we wanted to know whether our community of survivors and

caregivers had similar experiences to those described in Dr. Bristow's study. We wanted to understand what care women with ovarian cancer are receiving, as well as some reasons why women might not receive optimal treatment for this disease.

In order to better understand what women with ovarian cancer are experiencing, we reached out to our online community hosted by Inspire. In July 2013 we emailed approximately 14,000 community members, asking them to complete a survey about their diagnosis with and treatment for ovarian cancer. More than 1,000 people completed our survey. Some of the questions we asked replicated a survey the Alliance conducted in 2007 that received 1,700 responses, allowing us to compare patient perspectives over time.

Ovarian Cancer Diagnosis

Most of our respondents had been diagnosed with ovarian cancer between one and four years ago (51.45%). Half of respondents were diagnosed less than a month after they first sought medical attention. This is a substantial improvement over a previous survey conducted by the Alliance in 2007, in which only 40% of women reported a diagnosis within a month of seeking medical attention. About half as many women report waiting 6 months to a year for diagnosis (6.6% compared to 12% in 2007) or waiting more than a year for diagnosis (6.6% compared to 13%).

There were also small improvements from 2007 to 2013 in the number of doctors a woman consulted with before being diagnosed with ovarian cancer. Our survey found that 34.77% of women saw just one doctor (compared to 32% in 2007) and 39.56% saw two doctors (compared to 35% in 2007). Just 1.63% saw more than five doctors, compared to 5% in 2007. Most women reported that they

were diagnosed by a gynecologic oncologist (35.47%), with diagnosis by an obstetrician-gynecologist the second most common answer (26.48%).

Most cases of ovarian cancer are diagnosed when the disease is advanced; the Centers for Disease Control and Prevention reports that 61% of ovarian cancer cases are diagnosed when the disease has spread to distant organs or lymph nodes.³ A majority of women in our survey reported a diagnosis at stage III (55.23%) or stage IV (13.81%). Reports of an advanced diagnosis were more common in 2013 than 2007, when 50% of respondents were diagnosed at stage III and 11% at stage IV.

We speculated that the type of health insurance a woman had at her time of diagnosis might affect her treatment for ovarian cancer. The vast majority of our respondents (62.24%) had private insurance at the time of diagnosis. Only 5.18% had no insurance when they were diagnosed.

¹ American Cancer Society. *Cancer Facts & Figures 2013*. Atlanta: American Cancer Society; 2013. ² R. Bristow, J. Chang, A. Ziogas, H. Anton-Culver. "NCCN treatment guidelines for ovarian cancer: A population-based validation study of structural and process quality measures." *Gynecologic Oncology*, Volume 130, Issue 1, July 2013, Page e18 ³ Howlader N, Noone AM, Krapcho M, Garshell J, Neyman N, Altekruse SF, Kosary CL, Yu M, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2010, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2010/, based on November 2012 SEER data submission, posted to the SEER web site, 2013.

Ovarian Cancer Treatment

Our survey asked whether women knew about and received standard-of-care treatment for ovarian cancer, namely surgery followed by six cycles of chemotherapy. We also wanted to learn whether women were being treated by a gynecologic oncologist, as studies have shown improved survival for women who receive treatment from these specialists. Finally, we wanted to understand why some women did not receive optimal care.

Overall, our survey found far more women reporting that they received standard-of-care treatment compared to the study conducted by Bristow, et al. A vast majority of our respondents (80.42%) were told that the standard treatment for ovarian cancer is surgery followed by six rounds of chemotherapy, and nearly three in four women reported receiving that treatment (72.8%). Most women (79.48%) did receive a referral to see a gynecologic oncologist, and nearly all women (90.19%) reported being treated by a gynecologic oncologist. This is an increase from our 2007 survey, when 80% of women reported that their surgery was performed by a gynecologic oncologist.

Among the 94 women who did not receive treatment from a gynecologic oncologist, the most common reason was a woman not knowing that this was recommended (34.04%). Inability to travel the distance to see a specialist was the second-most common reason given (11.70%). Most women reported receiving treatment within 15 miles of their home (43.91%), however 16.50% traveled more than 60 miles for treatment.

The study by Bristow, et al, found that women were more likely to receive standard-of-care treatment for ovarian cancer when treated at a facility that saw a high volume of patients with the disease. Since patients are not likely to know how many ovarian cancer cases their medical center sees annually, we instead asked respondents to identify whether they had been treated at one of the 67 NCI Designated Cancer Centers found in the United States. A total of 224 respondents (21.96%) reported that they had been treated at one of these centers, with the highest number of patients at Memorial Sloan Kettering, the University of Texas MD Anderson Cancer and Dana Farber/Harvard Cancer Center.

Discussion:

While the results from our patient survey appear to be more encouraging than those of the study conducted by Bristow, et al, there are several reasons that may have occurred. Our respondents were self-selected and are not a representative sample of women diagnosed with ovarian cancer in the United States (see Limitations, page 5). As such, our data may not paint an accurate picture of the state of ovarian cancer diagnosis and treatment in this country.

It seems likely that the women in our survey represent the population that does get standard-of-care treatment: white women who had health insurance at the time of their diagnosis and have attained a higher level of education than the United States average. Further research into populations that were not represented in our respondents—especially those who are less connected to support services and lack health insurance—would be needed to confirm whether this is the case.

We know that about one in four women diagnosed with ovarian cancer will die within a year of their diagnosis. Given that 83.35% of our respondents were diagnosed more than a year ago, we may have underrepresented those women who passed away within the first year, perhaps due to a lack of proper treatment. Further studies of women who are newly diagnosed might reveal more about what women are told about standard treatment for ovarian cancer and why they do—or do not—receive such care.

Comparing survey responses from 2007 and 2013 showed several areas of improvement, but also some cause for concern. More women reported being diagnosed with stage III or IV ovarian cancer—an advanced state with much lower survival rates. On the other hand, women report that they are being diagnosed more rapidly and after seeing fewer doctors, an encouraging trend. In addition, more women reported being treated by a gynecologic oncologist than in 2007—a trend that should improve survival outcomes.

More research is needed to determine which populations of women are not receiving standard of care treatment for ovarian cancer, and why that is the case. However, our survey does provide a patient perspective on diagnosis and treatment, and reveals a few encouraging trends around prompt diagnosis.

Limitations:

Our survey was publicized only within our Inspire community and was open to anyone who wished to respond. As a result, our respondents are self-selected and are not a representative sample of women diagnosed with ovarian cancer in the United States.

Our community on Inspire is predominantly female; as of August 6, 2013, we had 12,516 women in our community and 1,190 men, representing 87.4% and 8.3% respectively (an additional 610 people have declined to share their gender publicly). Most of our members fall between the ages of 35 and 64. (See table below for detailed breakdown of our demographics on Inspire.)

Age	Female	Male	Hidden	Total
Under 18	16	3	9	28
18 - 24	268	33	27	328
25 - 34	1466	170	88	1724
35 - 44	2462	254	133	2849
45 - 54	3476	254	162	3892
55 - 64	3243	294	122	3659
65 - 79	1518	167	58	1743
80 and over	67	15	11	93
Total	12516	1190	610	14316

Our respondents are younger than the average woman with ovarian cancer and more likely to identify as white/Caucasian. The median age of ovarian cancer diagnosis in the United States is 63 years,⁴ while the median age of our survey respondents was 56.5 years. The vast majority of our respondents identify themselves as white/Caucasian (91.1% of respondents). While white women have the highest rates of ovarian cancer, they are overrepresented in this survey.⁵

4 Howlander N, Noone AM, Krapcho M, Garshell J, Neyman N, Altekruse SF, Kosary CL, Yu M, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2010, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2010/, based on November 2012 SEER data submission, posted to the SEER web site, 2013. 5 <http://www.cdc.gov/cancer/ovarian/statistics/race.htm>

The people who responded to our survey also differ from the overall United States population. They are more educated and less likely to be uninsured or insured under Medicaid. Just 5.18% of our respondents had no health insurance at the time they were diagnosed with ovarian cancer; the US Census reports that in 2010, 17.4% of the population was uninsured.⁶ Our respondents were more likely to have completed some college (20.12%), a college degree (31.85%) or post-graduate studies (36.19%) as compared to the general population (16.8%, 19.4% and 10.5%, respectively).⁷

As noted above, more research into populations not captured by this survey is needed to fully understand which women in the United States are receiving standard-of-care treatment for ovarian cancer, and why that is the case.

Patient Voices:

Comments from the women and caregivers who responded to our survey elaborate on these findings. These patient voices provide further insight into the experience of being diagnosed with and treated for ovarian cancer. While a majority of the comments were positive, many reflected the challenges of misdiagnosis and the difficulty of coping with treatments for this disease. A number of women felt they did not receive complete or accurate information about their treatment options. Following are a sampling of patient voices from our survey.

Most of our respondents reported being diagnosed quickly and receiving treatment from a gynecologic oncologist.

“My gynecologist did everything exactly right. She ordered the right tests (transvaginal ultrasound, CA-125, CT scan) and then when ovarian cancer was suspected, she referred me to a gyn/onc.”

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“I had my first surgery three weeks after my initial visit with my internist. I have had three surgeries, three recurrences in 2 1/2 yrs, and [am] presently in chemo. I have educated myself, and been a strong participant in my treatment, and realize I have been lucky that I had surgery so quickly, and my team is so willing to explain everything to me, and speak to my concerns. In the beginning, you are not able to ask the questions or know the treatment you should be getting, so your place of treatment is so important.”

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“My primary care physician recognized my symptoms and sent me directly to a gyn/onc. My journey has not been easy, but I am grateful that I was diagnosed early.”

6 O'Hara, Brett and Kyle Caswell, P70-133, “Health Status, Health Insurance, and Medical Services Utilization: 2010,” Current Population Reports, U.S. Census Bureau, Washington, DC, 2012. 7 U.S. Census Bureau, Statistical Abstract of the United States: 2012 (131st Edition) Washington, DC, 2011; <http://www.census.gov/compendia/statab/>.

“I received excellent care. My OB-GYN, surgeon and oncologist were all top notch. Even in this small town (60,000), we have a great cancer center and excellent doctors. They all know each other and work together seamlessly as a team. They stay up-to-date with the latest research. We did not have a gyn-onc in the region until I was finished with treatment, but I’ve not been convinced, over the years since then, that she is any better than my team.”

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“My primary doctor had blood tests done on the day I went in feeling bloated and constipated. She had the CT scan done by the end of the week. She had the results within two hours and called me personally. She had already contacted my gynecologist who then called within the hour and met with me 30 minutes later. He then contacted the gynecological oncologist with me sitting in the room. I had an appointment the following week and surgery one week after my initial exam by the primary doctor. I had the surgery and then chose a medical oncologist who monitored the chemotherapy. After my six chemos, I made regular visits to both the gynecologic oncologist and the medical oncologist for the next five years.”

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“My PCP physician sent me for a CT scan and told me that it was most probably ovarian cancer but would be confirmed by gynecologic oncologist. Gynecologic oncologist did the surgery but he does not do the chemotherapy so he referred me to medical oncologist. I found that for first-line therapy it was okay to have a medical oncologist since it was so standard. But now that I’m recurring, I’ve changed to a gynecologic oncologist that does both surgery and therapy.”

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“I was very fortunate to be at the care of an extremely competent gynecology/oncology surgeon. I would not be here today if it wasn’t for him. It saddens me that it took so long to get the diagnosis even when my ob/gyn knew that I am high-risk and BRCA1+.”

However, misdiagnosis continues to be a problem with ovarian cancer, as reported by a number of respondents.

“Despite my primary care doctors being a midwife and ob/gyn my symptoms were ignored and misdiagnosed for well over a year. I kept trying new doctors and nurses to no avail. Not until I had terrible ascites did I get a CT scan and was finally diagnosed. Beyond frustrating.”

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“I received swift and immediate treatment once diagnosed with ovarian cancer but the initial diagnosis took some time to get to. It was initially thought to be a bowel obstruction. I think it is important to get better tools to diag

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“ My ob/gyn was terrible, she refused to examine me and said it was all in my head. It wasn’t until my stomach was distended, and I felt pregnant, which was not possible as I had a partial hysterectomy, that I went to my GP. He got me into the hospital immediately. I had two tumors that my new gyn/onc found that were twisted. He operated immediately, and kept me as a patient ever since. I would have died if I listened to my old ob/gyn. I am glad I trusted myself to follow through on my own.”

Some women reported that they were given incomplete or incorrect information about their treatment options.

“I was not referred to [a] gyn oncologist for my surgery. I didn’t know there was such a thing. I had [a] total hysterectomy for pain, bleeding, and a large mass. By the time I had the surgery I could feel the mass moving while walking. After surgery [I] was told it was cysts and endometriosis.... The next day my gyn called and said he had bad news and would have to refer me to [a] gyn oncologist with an appointment the very next day. I was then told I had cancer on both ovaries and one was [the] size of [an] orange. I would have to have a second surgery if I wanted to be staged. He told me the treatment was the same no matter what I decided. I had a hard time with original surgery and opted not to be staged.”

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“I was very upset that I wasn’t told that I’d have to have chemo and radiation until I went in for my eight week check-up, post surgery. I thought I was going back to work the following Monday. I felt great and could walk well. At the eight week post-surgery appointment, it was highly recommended that I begin chemo and radiation immediately, as in the next day, and it would give me an extra 10 to 15% survival chance. It was more than recommended, it was ‘YOU MUST DO THIS.’ I signed a sheet of paper with paragraphs of side effects and gave it back that day, as they drew permanent marker lines on me for radiation, as I cried, worried if I’d keep my job, as I told my employer I was returning to work. Doctors need to be fair with patients, and give them adequate information.”

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“I wasn’t given much information, so I sort of drifted through treatment like a zombie. I had numerous side effects and complications in the first year, but was fortunate to achieve remission quickly and remain in remission for seven years. Upon recurrence, which occurred after I moved to a different city, I began to hear terms and ideas no one had shared before. I could have probably greatly reduced the horrid neuropathy and other permanent complaints with more information.”

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“The gynecologist who initially diagnosed did not go over treatment options nor refer me to a gyn oncologist even though I am in a major city with two major centers. He wanted to do surgery even though he was a chief resident. I self-referred myself to Mass General the next day and saw the head of the gyn oncology department the day after who went over all options and performed the surgery five days later... I still can’t believe that I was not immediately referred elsewhere, but am thankful that I was proactive.”

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“The surgeon (who did the emergency surgery) was very adamant that I should stay local (there are no gyn/onc here, just one oncologist) as going to the ‘mega hospital [MD Anderson]’ would only result in not being treated here at the ER should I have a problem. My husband and I were very confused as to where to go. Upon the insistence of my children we went to MD [Anderson]. I don’t know if they had not intervened, I would have made that decision... and wonder if the outcome (I’m alive) would have been different? I often would like to call my old gynecologist (of several years) and share what I have learned so she can better understand ovarian cancer. Possibly even call the surgeon and explain that being treated by a gynecologic oncologist increases a woman’s chances of surviving ovarian cancer.”

Women who did not receive treatment from a gynecologic oncologist reported that it was due to lack of knowledge or the distance they would have needed to travel for treatment.

“I went to [the] ER due to extreme pain and went into surgery within a few hours. I was not told I had cancer until afterwards. And was never seen [by] or told to see an oncologist. Only after questioning [my doctor] did he recommend I see [an] oncologist.”

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“I saw [a] gyn/onc and then received treatment from [an oncologist]. It was too far to drive.”

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“I was treated by a medical oncologist (in contrast to an oncologist specialized in surgeries) but he is not [a] gynecologist. In the town where I live there are very few medical oncologists, maybe two.”

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“My Hysterectomy was done by a gynecologic oncologist and it wasn’t until after the surgery [that] they discovered it was cancer. Initially they thought it would be benign. After surgery I didn’t feel the need to travel to Seattle for chemo so he recommended a regular oncologist close to home.

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“I wanted to be close to home for treatment.”

“The survey launched by the Ovarian Cancer National Alliance is a very important step forward in understanding the level and quality of care provided to women with ovarian cancer in the United States. Given the impact of appropriate upfront care on the clinical outcome of women with ovarian cancer, such efforts coupled with improving access to appropriate specialists for the highest level of care will be essential.”

Anil K. Sood, MD

Director, Blanton-Davis Ovarian Cancer Research Program, MD Anderson Cancer Center

Survey Data

How long has it been since you were first diagnosed with ovarian cancer?

Answer	Number	Percentage
Less than one year	178	16.65%
Between one and four years	550	51.45%
Between four and seven years	203	18.99%
Between seven and 10 years	71	6.64%
More than 10 years	67	6.27%
Total	1069	

What health insurance, if any, did you have at the time you were initially diagnosed? Choose all / any that apply.

Answer	Number	Percentage
Medicare	160	13.37%
Private insurance	745	62.24%
Supplemental insurance	96	8.02%
Medicaid	14	1.17%
No insurance	62	5.18%
Other	120	10.03%
Total	1197	

How much time did it take from when you first sought medical attention until you were diagnosed with ovarian cancer?

Answer	Number	Percentage
Less than one month	523	50.00%
One month	126	12.05%
Two months	102	9.75%
Three months	73	6.98%
3-6 months	84	8.03%
6-12 months	69	6.60%
More than one year	69	6.60%
Total	1046	

What type of doctor diagnosed your initial ovarian cancer?

Answer	Number	Percentage
Ob/gyn	277	26.48%
Family physician	166	15.87%
Oncologist	48	4.59%
Gynecologic oncologist	371	35.47%
Not sure / don't recall	14	1.34%
Other	170	16.25%
Total	1046	

How many doctors did you consult with before receiving a diagnosis of ovarian cancer?

Answer	Number	Percentage
One	363	34.77%
Two	413	39.56%
Three	193	18.49%
Four	41	3.93%
Five	17	1.63%
More than five	17	1.63%
Total	1044	

What stage was your cancer when it was initially diagnosed?

Answer	Number	Percentage
Stage I	184	17.64%
Stage II	112	10.74%
Stage III	576	55.23%
Stage IV	144	13.81%
Not sure / don't recall	27	2.59%
Total	1043	

Were you told that standard treatment for ovarian cancer is surgery followed by six rounds of chemotherapy?

Answer	Number	Percentage
Yes	834	80.42%
No	158	15.24%
Not sure / don't recall	45	4.34%
Total	1037	

Did you receive standard treatment for ovarian cancer (surgery followed by six rounds of chemotherapy)?

Answer	Number	Percentage
Yes	746	72.08%
No	282	27.25%
Not sure / don't recall	7	0.68%
Total	1035	

Did the doctor who diagnosed you with ovarian cancer give you a referral to see a gynecologic oncologist?

Answer	Number	Percentage
Yes	821	79.48%
No	203	19.65%
Not sure / don't recall	9	0.87%
Total	1033	

Did you receive treatment from a gynecologic oncologist?

Answer	Number	Percentage
Yes	929	90.19%
No	91	8.83%
Not sure / don't recall	10	0.97%
Total	1030	

Why did you not receive treatment from a gynecologic oncologist?

Answer	Count	Percentage
I didn't know this was recommended	32	34.04%
My doctor said I didn't need to see a specialist	8	8.51%
My insurance wouldn't cover care by a gynecologic oncologist	0	0.00%
I couldn't travel to the nearest gynecologic oncologist	11	11.70%
I preferred to be treated by another doctor	9	9.57%
Other	34	36.17%
Total	94	

Where did you receive treatment for your ovarian cancer? Please select from the following options.

Answer	Count	Percentage
Abramson Cancer Center, University of Pennsylvania (1)	2	0.16%
Albert Einstein Cancer Center, Yeshiva University (2)	2	0.16%
Alvin J. Siteman Cancer Center, Washington University and Barnes-Jewish Hospital (3)	1	0.08%
Arizona Cancer Center, University of Arizona (4)	1	0.08%
The Barbara Ann Karmanos Cancer Institute, Wayne State University School of Medicine (5)	0	0.00%
The Cancer Institute of New Jersey, Robert Wood Johnson Medical School (6)	3	0.24%
Cancer Therapy & Research Center, University of Texas Health Science Center (7)	0	0.00%
Case Comprehensive Cancer Center, Case Western Reserve University (8)	0	0.00%
Chao Family Comprehensive Cancer Center, University of California, Irvine (9)	3	0.24%
City of Hope Comprehensive Cancer Center (10)	3	0.24%
Cold Spring Harbor Laboratory Cancer Center (11)	0	0.00%
The Comprehensive Cancer Center of Wake Forest University (12)	0	0.00%
Dan L. Duncan Cancer Center, Baylor College of Medicine (13)	0	0.00%
Dana-Farber/Harvard Cancer Center (14)	17	1.39%
David H. Koch Institute for Integrative Cancer Research at MIT (15)	0	0.00%
Duke Cancer Institute, Duke University Medical Center (16)	2	0.16%
Eppley Cancer Center, University of Nebraska Medical Center (17)	0	0.00%
Fox Chase Cancer Center (18)	4	0.33%
Fred Hutchinson/University of Washington Cancer Consortium (19)	3	0.24%
Georgetown Lombardi Comprehensive Cancer Center (20)	1	0.08%
H. Lee Moffitt Cancer Center & Research Institute (21)	6	0.49%
Harold C. Simmons Cancer Center, University of Texas Southwestern Medical Center (22)	0	0.00%
Herbert Irving Comprehensive Cancer Center, Columbia University (23)	0	0.00%
Holden Comprehensive Cancer Center, University of Iowa (24)	6	0.49%
Hollings Cancer Center, Medical University of South Carolina (25)	0	0.00%
Huntsman Cancer Institute, University of Utah (26)	3	0.24%
Indiana University Melvin and Bren Simon Cancer Center (27)	3	0.24%
The Jackson Laboratory Cancer Center (28)	0	0.00%
Jonsson Comprehensive Cancer Center, University of California at Los Angeles (29)	3	0.24%
Kimmel Cancer Center, Thomas Jefferson University (30)	3	0.24%
Knight Cancer Institute, Oregon Health and Science University (31)	2	0.16%
Masonic Cancer Center, University of Minnesota (32)	4	0.33%
Massey Cancer Center, Virginia Commonwealth University (33)	0	0.00%
Mayo Clinic Cancer Center (34)	11	0.90%
Memorial Sloan-Kettering Cancer Center (35)	27	2.20%
Norris Cotton Cancer Center at Dartmouth (36)	2	0.16%
NYU Cancer Institute (37)	4	0.33%
The Ohio State University Comprehensive Cancer Center (38)	6	0.49%
Purdue University Center for Cancer Research (39)	0	0.00%
Robert H. Lurie Comprehensive Cancer Center, Northwestern University (40)	8	0.65%
Roswell Park Cancer Institute (41)	2	0.16%
Salk Institute Cancer Center (42)	0	0.00%
Sanford-Burnham Medical Research Institute (43)	0	0.00%

Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University (44)	6	0.49%
St. Jude Children's Research Hospital (45)	0	0.00%
Stanford Cancer Institute (46)	3	0.24%
The Wistar Institute Cancer Center (47)	0	0.00%
UAB Comprehensive Cancer Center, University of Alabama at Birmingham (48)	4	0.33%
UC Davis Comprehensive Cancer Center (49)	6	0.49%
UC San Diego Moores Cancer Center (50)	3	0.24%
UCSF Helen Diller Family Comprehensive Cancer Center (51)	3	0.24%
UNC Lineberger Comprehensive Cancer Center (52)	1	0.08%
The University of Chicago Comprehensive Cancer Center (53)	0	0.00%
University of Colorado Cancer Center (54)	3	0.24%
University of Hawaii Cancer Center (55)	0	0.00%
The University of Kansas Cancer Center (56)	2	0.16%
University of Maryland Marlene and Stewart Greenebaum Cancer Center (57)	0	0.00%
University of Michigan Comprehensive Cancer Center (58)	11	0.90%
University of New Mexico Cancer Center (59)	0	0.00%
University of Pittsburgh Cancer Institute (60)	3	0.24%
The University of Texas MD Anderson Cancer Center (61)	18	1.47%
University of Virginia Cancer Center (62)	5	0.41%
University of Wisconsin Carbone Cancer Center (63)	14	1.14%
USC Norris Comprehensive Cancer Center (64)	0	0.00%
Vanderbilt-Ingram Cancer Center (65)	2	0.16%
Winship Cancer Institute, Emory University (66)	3	0.24%
Yale Cancer Center (67)	5	0.41%
Total treated at NCI Cancer Center	224	21.96%
other	796	78.04%
Total	1020	

How many miles was the place you received treatment from your home?

Answer	Number	Percentage
Less than 15 miles	447	43.91%
15-30 miles	250	24.56%
30-60 miles	153	15.03%
More than 60 miles	168	16.50%
Total	1018	

I am a:

Answer	Number	Percentage
Woman diagnosed with ovarian cancer	886	87.03%
Caregiver or family member answering on behalf of a patient	132	12.97%
Total	1018	

Please indicate your age

Calculation	Result
Count	1016
Average	56.51
Minimum	23
1st quartile	51
2nd quartile	57
3rd quartile	64
Maximum	91

Please indicate your race / ethnicity

Answer	Number	Percentage
White/Caucasian	925	91.13%
Black or African-American	13	1.28%
American Indian	3	0.30%
Hispanic or Latino	17	1.67%
Asian	27	2.66%
Other	21	2.07%
No answer	9	0.89%
Total	1015	

What is the highest level of education you have completed?

Answer	Number	Percentage
Some high school	9	0.89%
High school	93	9.17%
Some college	204	20.12%
College	323	31.85%
Post-graduate studies	367	36.19%
No answer	18	1.78%
Total	1014	