

***CURE* Rare Cancer Survey:  
April 2009**

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### **Methodology**

This document provides a summary of major findings from an online survey conducted among 1,365 *CURE* magazine subscribers who self-identified as having cancer. The survey, supported by Novartis Oncology, was conducted between December 2008 and January 2009 to compare and contrast the attitudes of rare cancer patients and non-rare cancer patients. This report focuses on these differences from the perspective of the rare cancer patient. Detailed tables that provide answers to select questions are included in the appendix.

The research was done by RF Insights, a research and polling consultancy. RF Insights is a member of the Ruder Finn Group, one of the world's largest independent strategic communications and public relations networks. The RF Insights team includes industry research experts who regularly conduct statistically-significant research on healthcare issues. The margin of error for the entire sample is +/- 3.0%.

- 426 respondents self-identified themselves as having “rare cancer.” Rare cancer patients were self-identified and then cross-referenced with statistics from the Center of Disease Control (CDC) and the American Cancer Society (ACS) to confirm designation as a “rare cancer” patient, based on cancer type. According to the CDC and ACS, fewer than 35,000 cancer patients have rare cancers. The margin of error for this group is +/- 4.7%.
- 939 respondents identified themselves as having “non-rare cancer.” The margin of error for this group is +/- 3.2%.

*CURE* has access to an online survey panel that includes 4,317 cancer patients and survivors that have been diagnosed with a wide variety of tumor and cancer types. To control bias, each member of the panel was contacted by e-mail with a request to participate in a survey about cancer and was provided with a link that took them directly to a survey site. A high response rate of 32% was achieved.

### **About *CURE* Media Group**

*CURE* magazine is a free, award-winning publication from Dallas-based *CURE* Media Group – the national source for cancer patient education. By combining science and humanity, *CURE* helps patients, survivors and caregivers navigate the cancer journey and understand their diagnosis and treatment, while providing tools to cope during and after cancer, ultimately helping them to live the life they aspire to. Through the magazine, an annual resource guide for the newly diagnosed, books, and a new and interactive Website, *CURE* provides a wealth of resources for everyone on the cancer journey. *CURE* was chosen as one of min magazine's “Most Engaged Media Brands,” of 2009, honoring the strongest bonds between magazine brands and their readers. Visit [www.curetoday.com](http://www.curetoday.com) for more information.

## Major Findings

The major research findings are as follows:

- Rare cancer patients experience a high level of frustration over a.) the time it takes to get a correct diagnosis and b.) the conflicting information they receive about treatment options. This helps to explain why so many seek a second opinion. *(page 4)*
- Many rare cancer patients express concerns about the lack of access to reliable and credible information about their cancer and treatment options. This situation can forestall meaningful discussions with doctors and leave rare cancer patients dissatisfied with the process of obtaining the information they want and need. *(page 5)*
- Rare cancer patients feel less in control of their cancer compared to non-rare cancer patients. But those rare cancer patients who do feel in control offer sound advice that others in similar situations can follow and learn from. *(page 6)*
- Rare cancer patients are more likely than non-rare cancer patients to say it is important to have a multi-disciplinary team of health professionals working together on their treatment. They say access to other professionals makes them feel better about their cancer treatment and more in control of their cancer. *(page 8)*
- Both rare cancer patients and non-rare cancer patients primarily turn to specialists and health-related Websites for information. The important difference between the two is that rare cancer patients are much more likely to turn to online social networking sites and blogs and to verify the credibility of these specialists/Websites. *(page 9)*

**1. Rare cancer patients experience a high level of frustration over a.) the time it takes to get a correct diagnosis and b.) the conflicting information they receive about treatment options. This helps to explain why so many seek a second opinion.**

Rare cancer patients are 2.2 times more likely than non-rare cancer patients to say they received multiple diagnoses before they received the final correct diagnosis. Rare cancer patients express frustration over the time it takes for them to receive a correct diagnosis.

- Nearly 1 in 3 **rare cancer patients** (31%) say they received multiple diagnoses compared to only 14% of **non-rare cancer patients**. This is a statistically significant difference
- Three in four **rare cancer patients** (75%) agree with the statement: *I was very frustrated by the difficulty I encountered in receiving a final, correct diagnosis*
- The average **rare cancer patient** was provided with nearly three diagnoses (2.9) before they received the final correct diagnosis
- The time between first seeking medical attention and receiving a final diagnosis was nearly six months (5.75) for the average **rare cancer patient**

Rare cancer patients are also more likely than non-rare cancer patients to say they have received conflicting information about treatment options. This frustration helps explain why rare cancer patients are much more likely to say it is important to get a second opinion about their treatment. Differences below are statistically significant.

- Many more **rare cancer patients** (41%) than **non-rare cancer patients** (35%) say they have faced a situation where they received conflicting information about their cancer and treatments options
- **Non-rare cancer patients** (60%) are much more likely than **rare cancer patients** (48%) to say that getting a second opinion about their cancer and treatment options is VERY important

**2. Many rare cancer patients express concerns about the lack of access to reliable and credible information about their cancer and treatment options. This situation can forestall meaningful discussions with doctors and leave rare cancer patients dissatisfied with the process of obtaining the information they want and need.**

**Rare cancer patients** are more likely than **non-rare cancer patients** to say they lack access to credible and reliable information about their condition. This can cause many to “feel alone” in dealing with their disease and leave them questioning what information they should ask of their doctor or doctors. All of the following are differences that are statistically different.

- Patients with **rare cancer** are more likely (39%) than **non-rare cancer** patients (29%) to agree with the statement: *I often feel that I am left alone in my search for reliable and credible information.*
- Patients with **rare cancer** are more likely (74%) than **non-rare cancer** patients (62%) to STRONGLY agree with the statement: *It is up to me to be my own disease management advocate*
- Patients with **rare cancer** are more likely (35%) than **non-rare cancer** patients (29%) to agree with the statement: *I sometimes feel in the dark about which questions I should ask my doctor about my cancer*

When thinking about the diagnosis and treatment of their cancer, **rare cancer patients** are 30% less likely than **non-rare cancer patients** to say they are VERY satisfied with access to credible and reliable information and treatments options.

- Less than half of **rare cancer patients** (47%) say they are VERY satisfied, with access to credible and reliable information and treatments options compared to 61% of **non-rare cancer patients**. This represents a statistically significant difference

### 3. Rare cancer patients feel less in control of their cancer compared to non-rare cancer patients. But those rare cancer patients who do feel in control offer sound advice that others in similar situations can follow and learn from.

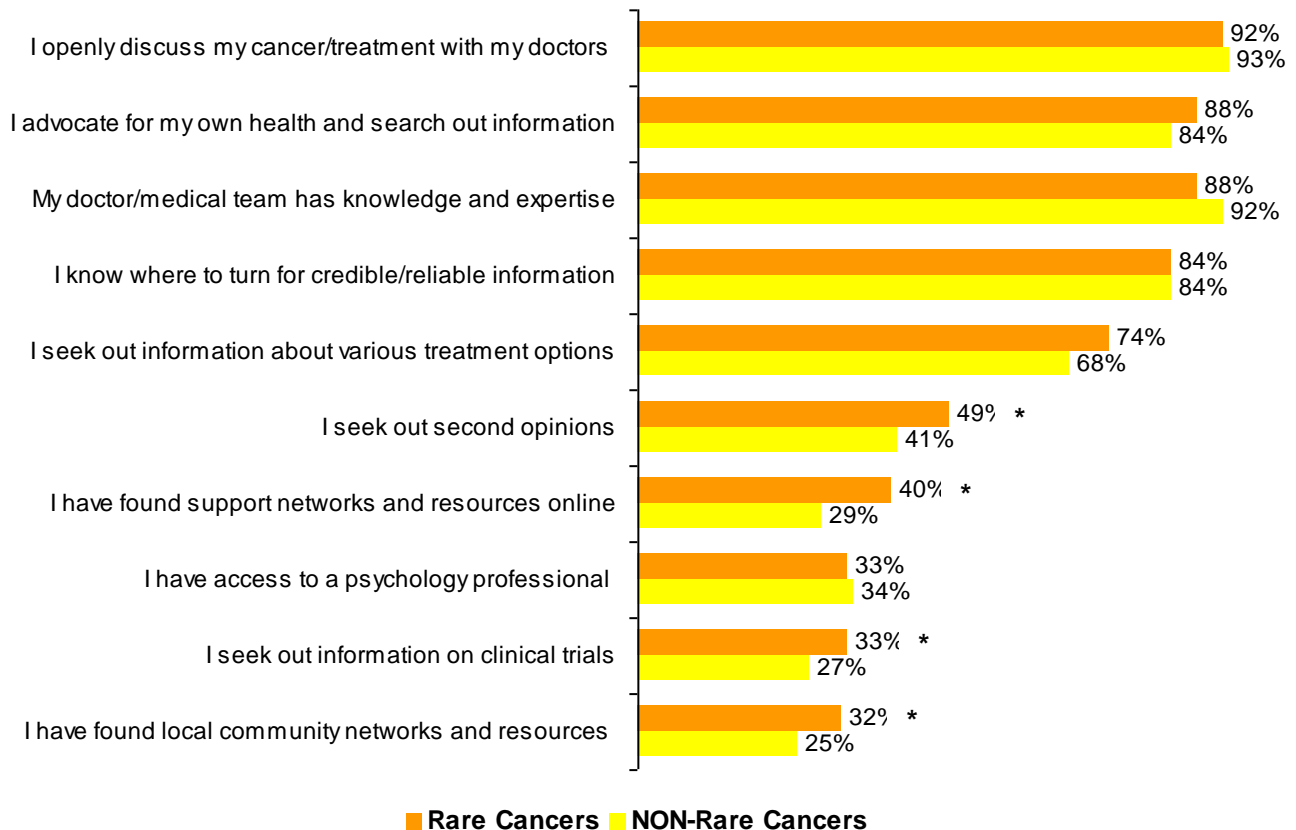
Rare cancer patients are 30% more likely than non-rare cancer patients to say they do NOT personally feel “in control” of their cancer.

- Nearly 1 in 3 rare cancer patients (34%) say they do NOT personally feel in control of their cancer, compared to 26% of non-rare cancer patients. This is a statistically significant difference.

It is critical for rare cancer patients struggling to take control of their disease to hear from those who have found ways to better meet the challenges posed by their diagnosis. This advice given by rare cancer patients regarding personal control can help guide other patients who need direction.

The following graph lists the “major” reasons why cancer patients feel they are in control of managing their cancer. The asterisk denotes significant differences between the two groups.

**Major Reasons Cancer Patients Feel in Control of Their Cancer**



## ***Rare Cancer Patients Compared to Non-Rare Cancer Patients***

Some reasons for feeling in control are more important to rare cancer patients compared to non-rare cancer patients. The following represent statistically significant differences:

- Nearly half of **rare cancer patients** (49%) say, “I have sought out second opinions,” is a major reason for feeling in control, compared to 41% of **non-rare cancer patients**
- Two in five **rare cancer patients** (40%) say, “I have found support networks and resources online,” is a major reason for feeling in control, compared to only 29% of **non-rare cancer patients**
- One in three **rare cancer patients** (33%) say, “I have sought out information on clinical trials,” is a major reason for feeling in control, compared to 27% of **non-rare cancer patients**
- One in three **rare cancer patients** (32%) say, “I have found local support networks and resources in my community,” is a major reason for feeling in control, compared to 25% of **non-rare cancer patients**

- 4. Rare cancer patients are more likely than non-rare cancer patients to say it is important to have a multidisciplinary team of health professionals working together on their treatment. They say access to other professionals makes them feel better about their cancer treatment and more in control of their diagnosis.**

### ***Rare Cancer Patients Compared to Non-Rare Cancer Patients***

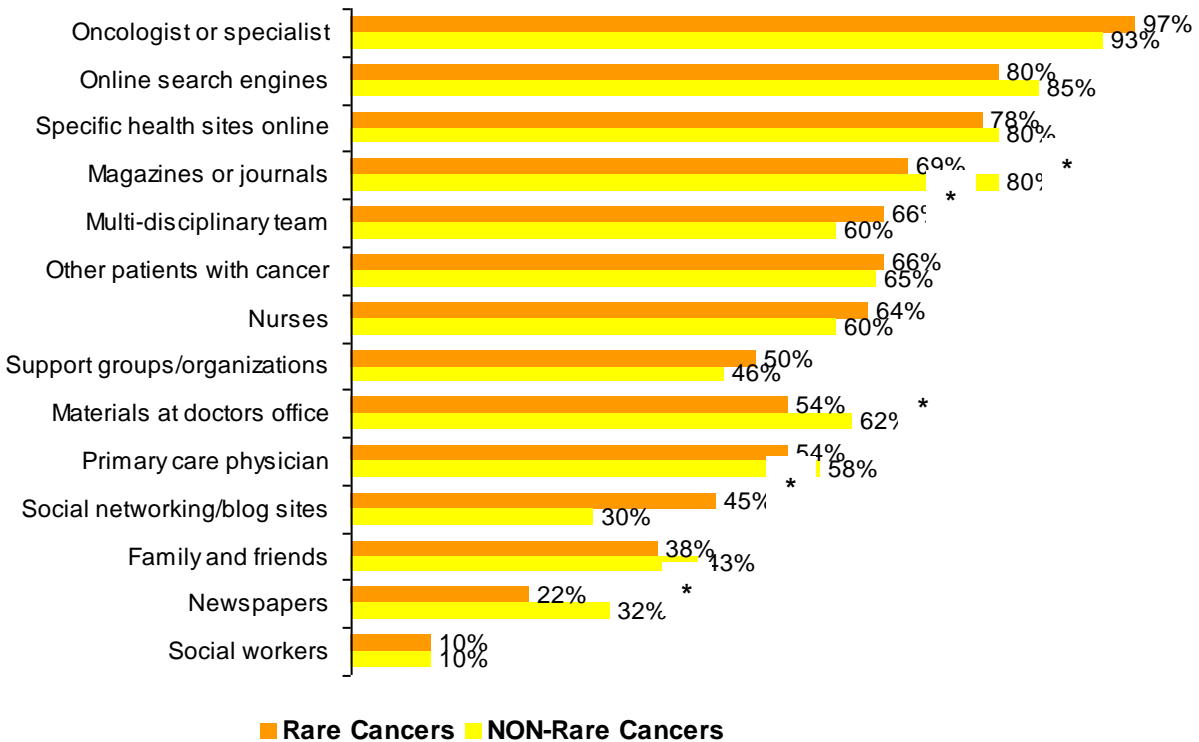
Rare cancer patients are more likely than non-rare cancer patients to want the doctor they see most to seek advice from other specialists and health professionals about their treatment. The following differences all represent statistically significant differences.

- **Rare cancer patients (58%)** are nearly 1 ½ times more likely as **non-rare cancer patients (40%)** to say it is VERY important that cancer patients ask the physician they see most often to seek advice from other physicians regarding their personal treatment plan
- **Rare cancer patients (58%)** are nearly twice as likely as **non-rare cancer patients (31%)** to say they have specifically asked the physician they see most often if he or she is seeking advice from other physicians
- Nearly all **rare cancer patients (96%)** say having the advice and counsel of a multidisciplinary team of physicians makes them feel better about their cancer treatment
- More than 9 in 10 **rare cancer patients (91%)** say that working and communicating with a team of health professionals makes them feel more in control of their diagnosis

**5. Both rare cancer patients and non-rare cancer patients primarily turn to specialists and health-related Websites for information. The important difference between the two is that rare cancer patients are much more likely to turn to online social networking sites and blogs and to verify the credibility of these specialists/Web sites.**

As the following graph lists illustrates, specialists and health Web sites top the list of information sources cancer patients use to retrieve information about their cancer and treatment options.

**Where Patients Turn for Information  
(Percentage "very often" or "sometimes")**



## ***Rare Cancer Patients Compared to Non-Rare Cancer Patients***

The above ranking of information sources looks very similar for non-rare cancer patients with one important exception: rare cancer patients are 50% more likely than non-rare cancer patients to ***turn to online social networking sites and blogs***. The following are statistically significant differences.

- More than 2 in 5 rare cancer patients (45%) say they “very often” or “sometimes” turn to social networking sites and blogs for information, compared to only 30% of non-rare cancer patients
- In fact, rare cancer patients (22%) are twice as likely as non-rare cancer patients (10%) to say they go online “very often” to social networking sites or blogs for information about their cancer

Other statistically significant results indicate that rare cancer patients are more likely to “go online” in search of information about their cancer because they may have difficulty finding it through traditional channels.

- Patients with rare cancer are nearly twice as likely (39%) than non-rare cancer patients (22%) to agree with the statement: *I have turned to online social networking sites for information because of difficulties finding information from other sources*

## ***Rare Cancer Patients Find Social Networking Sites and Blogs More Credible***

Both rare cancer and non-rare cancer patients find oncologists/specialists, online health sites and nurses to be highly credible sources. Rare cancer patients, however, are statistically more likely than non-rare cancer patients to say that online social networking sites and blogs are credible sources of information.

- A majority of **rare cancer patients** (51%) say that social networking sites and blogs provide credible information, compared to only 38% of **non-rare cancer patients**
- In fact, **rare cancer patients** are more than twice as likely (11%) as **non-rare cancer patients** (5%) to say they provide VERY credible information

## **CURE Rare Cancer Survey: Detailed Appendix**

The following pages include answers to select questions from the CURE Media Group Rare Cancer Survey segmented by rare cancer patients and non-rare cancer patients.

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**DETAILED TABLES**

**1. Cancer Type**

What type of cancer were you diagnosed with?	All (%)
Other	44
Breast	16
Non-Hodgkin Lymphoma	11
Ovarian	8
Sarcoma	8
Endometrial	6
Colon/Rectal	4
Pancreatic	4
Melanoma	4
Leukemia (CML)	4
Common cancer with rare situation	4
Lung	3
Skin (non-melanoma)	3
Bladder	2
Prostate	2
Skin	2
Kidney/Renal	2
Leukemia (ALL)	2
Gastric	1

**2. Getting Diagnosed**

Were you given a correct diagnosis for your cancer immediately or did you receive several diagnoses before you received the final correct diagnosis?	Non-Rare Cancers (%)	Rare Cancers (%)
Correct diagnosis immediately	<b>86</b>	<b>69</b>
Multiple diagnoses	<b>14</b>	<b>31*</b>

*\*Bolded numbers in the remainder of the document signify statistically significant differences.*

<b>IF MULTIPLE DIAGNOSES: How many diagnoses were you given before you received the final correct diagnosis?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
2	59	54
3	22	21
4	11	10
5	1	3
6	2	3
7	0	3
8	1	0
9	0	0
More than 10	3	0
Not sure	1	6

<b>How long was the time between when you first sought medical attention and then received a final diagnosis?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
<1 month	20	16
1-3 months	28	29
3-6 months	14	18
6-12 months	11	8
>12 months	3	6
More than a year	24	24

<b>IF SEVERAL DIAGNOSES: Do you agree or disagree with the following statement: I was very frustrated by the difficulty I encountered in receiving a final correct diagnosis?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Strongly agree	55	51
Somewhat agree	22	24
Somewhat disagree	8	6
Strongly disagree	12	18
Not sure	2	2

### 3. Sources of Information

#### Q. How often do you turn to each of the following for information about your cancer?

##### Rare Cancer Patients

Information Source	Very Often (%)	Sometimes (%)	Not Very Often (%)	Rarely (%)	Not Sure (%)
Oncologist or specialist	75	22	2	1	0
Online (Internet) search engines to get background information	45	35	13	7	0
Specific health sites online	43	35	9	13	0
Multi-disciplinary team of health professionals	35	31	12	21	1
Support groups/organizations	27	24	21	28	0
Other patients with cancer	27	39	16	17	1
Nurses	24	40	19	16	1
Primary care physician	23	32	15	29	1
Magazines or journals	23	46	18	12	1
Social networking/blog sites online	22	23	17	35	3
Written materials from doctors office	18	36	18	26	2
Family and friends	14	24	22	39	1
Newspapers	3	19	24	50	4
Social workers	2	9	18	66	5

##### Non-Rare Cancer Patients

Information Source	Very Often (%)	Sometimes (%)	Not Very Often (%)	Rarely (%)	Not Sure (%)
Oncologist or specialist	72	21	5	2	0
Online (Internet) search engines to get background information	45	40	8	7	0
Specific health sites online	41	39	11	8	1
Multi-disciplinary team of health professionals	33	27	16	20	4
Support groups/organizations	18	28	21	30	3
Other patients with cancer	21	44	16	17	2
Nurses	20	40	19	20	1
Primary care physician	23	36	17	24	0
Magazines or journals	30	50	12	8	0
Social networking/blog sites online	10	20	19	46	5
Written materials from doctors office	19	43	20	16	2
Family and friends	13	30	27	29	1
Newspapers	6	26	24	43	1
Social workers	2	8	15	66	9

<b>IF VERY OFTEN OR SOMETIMES FOR SPECIFIC HEALTH SITES: Which online health sites have you visited for information about your cancer, including treatment options?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Other	<b>31</b>	<b>40</b>
Cancer.org (American Cancer Society)	<b>25</b>	<b>17</b>
Cancer.gov (National Cancer Institute)	16	20
WebMD.com	12	8
Mayoclinic.com	10	6
NIH.gov	7	8

<b>IF VERY OFTEN OR SOMETIMES FOR SUPPORT GROUPS: Which support groups have you visited for information about your cancer, including treatment options?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Other	42	43
American Cancer Society	<b>33</b>	<b>20</b>
National Cancer Institute	14	18
Leukemia Lymphoma Society	<b>11</b>	<b>19</b>

<b>Which of the following information sources that you have NOT used or used only RARELY do you think would be helpful in dealing with your cancer?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Mental health support to deal with psychological impact of cancer	45	49
Multi-disciplinary team of health professionals	31	33
Support networks, including other patients with cancer	29	27
Specific health sites online	25	25
Social networking/blog sites online	21	22
Online (Internet) search engines to get background information	18	19

## 4. Perceived Credibility of Information Sources

**Q. How credible do you find each of the following information sources about your cancer, including treatment options?**

### Rare Cancer Patients

Information Source	Very Credible (%)	Somewhat Credible (%)	Not Very Credible (%)	Not at All Credible (%)	Not Sure (%)
Oncologist or specialist	86	12	1	1	0
Multi-disciplinary team of health professionals	56	31	3	3	7
Nurses	45	41	7	3	4
Support groups/organizations	36	49	5	3	7
Specific health sites online	35	52	8	1	4
Written materials from doctors office	35	48	6	4	7
Primary care physician	32	43	15	4	6
Other patients with cancer	28	53	10	4	5
Online (Internet) search engines to get background information	26	59	8	2	5
Magazines or journals	20	60	11	5	4
Social networking/blog sites online	11	40	21	11	17
Social workers	8	29	22	12	29
Family and friends	7	29	35	20	9
Newspapers	2	42	30	15	11

### Non-Rare Cancer Patients

Information Source	Very Credible (%)	Somewhat Credible (%)	Not Very Credible (%)	Not at All Credible (%)	Not Sure (%)
Oncologist or specialist	91	8	1	0	1
Multi-disciplinary team of health professionals	59	25	3	1	12
Nurses	48	40	5	1	5
Written materials from doctors office	45	44	6	1	4
Primary care physician	42	41	9	2	6
Specific health sites online	37	56	4	0	3
Support groups/organizations	28	52	9	2	9
Magazines or journals	27	60	9	2	2
Other patients with cancer	26	55	10	2	7
Online (Internet) search engines to get background information	24	63	8	2	3
Social workers	9	31	17	9	36
Family and friends	6	42	34	9	9
Social networking/blog sites online	5	33	25	12	25
Newspapers	4	44	31	10	11

## 5. Experiences With and Attitudes about the Health Professional Team

Do you know how many healthcare professionals are involved in your cancer treatment decisions?	Non-Rare Cancers (%)	Rare Cancers (%)
Yes	71	80
No	29	20

Below is a list of healthcare professionals. Which ones are you certain or 100% sure are involved in your treatment decisions?	Non-Rare Cancers (%)	Rare Cancers (%)
Surgeon/Surgical Oncologist	72	58
Primary Care Physician	42	39
Pathologist	43	40
Hematologist	30	36
Medical Oncologist	85	81
Radiation Oncologist	51	45
Nurse	42	49
Other	11	16

In your view, how good is communication and coordination of recommendations and delivery of care among the different healthcare professionals involved in your care?	Non-Rare Cancers (%)	Rare Cancers (%)
Very coordinated	52	55
Somewhat coordinated	37	35
Not coordinated	8	7
Don't know	2	3

Would you say that you have open communications with your doctor or medical team where you feel comfortable asking any questions?	Non-Rare Cancers (%)	Rare Cancers (%)
Yes	94	93
No	5	6
Not sure	1	1

Based on your experience, are you more comfortable discussing questions about your cancer with a nurse or a doctor?	Non-Rare Cancers (%)	Rare Cancers (%)
Nurse	79	80
Doctor	9	7
Not sure	12	13

How often have you faced a situation in which you felt you received conflicting information about your cancer and treatment options?	Non-Rare Cancers (%)	Rare Cancers (%)
All of the time	1	2
Frequently	5	7
Sometimes	29	32
Rarely	41	41
Never	<b>23</b>	<b>18</b>
Not sure	1	0

How often would you say you have received clear direction or advice from health professionals about your cancer and treatments?	Non-Rare Cancers (%)	Rare Cancers (%)
All of the time	<b>36</b>	<b>30</b>
Frequently	53	53
Sometimes	10	14
Rarely	1	2
Never	0	1
Not sure	0	0

How confident are you that you know the “right” questions to ask your doctor or doctors about your cancer?	Non-Rare Cancers (%)	Rare Cancers (%)
Very confident	40	40
Somewhat confident	52	51
Not very confident	6	9
Not at all confident	2	0
Not sure	0	0

How important is it to get second opinions about your cancer treatment?	Non-Rare Cancers (%)	Rare Cancers (%)
Very important	<b>48</b>	<b>60</b>
Somewhat important	35	31
Not very important	11	8
Not at all important	3	1
Not sure	3	0

**6. Level of Satisfaction with Care**

**Q. Thinking about the diagnosis and treatment of your cancer, how satisfied are you with each of the following?**

Rare Cancer Patients

Information Source	Very Satisfied (%)	Somewhat Satisfied (%)	Not Very Satisfied (%)	Not at All Satisfied (%)	Not Sure (%)
Diagnosis of a specific form of cancer	72	23	4	1	0
Open communications with my team, including doctors, nurses and social workers	68	26	3	3	0
Access to a team of health professionals	63	26	6	4	1
Clear direction and advise on treatment options	60	34	5	1	0
Second opinions	56	27	4	3	0
Access to credible and reliable information about my cancer and treatment options	47	40	40	3	0
Information about access to clinical trials	31	34	14	9	12
Support networks of patients who have a similar cancer	29	28	18	11	14
Emotional/psychological support	29	39	22	7	3

Non-Rare Cancer Patients

Information Source	Very Satisfied (%)	Somewhat Satisfied (%)	Not Very Satisfied (%)	Not at All Satisfied (%)	Not Sure (%)
Diagnosis of a specific form of cancer	76	19	3	1	1
Open communications with my team, including doctors, nurses and social workers	68	24	5	2	1
Clear direction and advise on treatment options	65	28	5	2	0
Access to a team of health professionals	64	25	7	3	1
Access to credible and reliable information about my cancer and treatment options	61	30	6	2	1
Second opinions	46	26	6	2	20
Information about access to clinical trials	31	29	19	7	16
Support networks of patients who have a similar cancer	31	32	16	6	15
Emotional/psychological support	30	33	20	10	7

**7. Agree Statements**

**Q. Do you agree or disagree with the following statements?**

Rare Cancer Patients

Statement	Strongly Agree (%)	Somewhat Agree (%)	Somewhat Disagree (%)	Strongly Disagree (%)	Not Sure (%)
Knowing more about my disease is the first step to being in control.	84	14	2	0	0
I feel more in control of my cancer when I have open communications with my doctor and medical team.	83	15	0	1	1
It is up to me to be my own disease management advocate.	74	18	4	3	1
I am comfortable with my doctor and healthcare team providing information and making decisions about my care.	61	27	9	3	0
Feeling “in control” is the best way to treat my cancer.	54	35	6	2	3
I am personally in control of my cancer.	47	35	9	6	3
I always know where to turn for credible and reliable information about my cancer.	42	45	10	3	0
I often feel that I am left alone in my search for reliable and credible information about my cancer.	15	24	23	36	2
I have turned to online social networking sites for information because of difficulties finding information from other sources.	14	24	20	38	4
I sometimes don’t know where to turn for credible and reliable information about my cancer.	9	20	27	41	3
I sometimes feel “left in the dark” about which questions I should ask my doctor about my cancer	9	26	25	39	1

## Non-Rare Cancer Patients

Information Source	Strongly Agree (%)	Somewhat Agree (%)	Somewhat Disagree (%)	Strongly Disagree (%)	Not Sure (%)
Knowing more about my disease is the first step to being in control.	86	13	1	1	0
I feel more in control of my cancer when I have open communications with my doctor and medical team.	85	12	1	1	1
I am comfortable with my doctor and healthcare team providing information and making decisions about my care.	64	26	8	2	0
It is up to me to be my own disease management advocate.	62	27	5	6	0
Feeling “in control” is the best way to treat my cancer.	55	33	7	4	1
I always know where to turn for credible and reliable information about my cancer.	48	39	10	3	0
I am personally in control of my cancer.	47	39	7	5	2
I often feel that I am left alone in my search for reliable and credible information about my cancer.	8	21	20	50	1
I sometimes feel “left in the dark” about which questions I should ask my doctor about my cancer.	7	22	21	49	1
I sometimes don’t know where to turn for credible and reliable information about my cancer.	6	19	19	53	3
I have turned to online social networking sites for information because of difficulties finding information from other sources.	6	16	21	52	5

8. Feeling in Control of Cancer

Would you say that you personally feel “in control” of your cancer?	Non-Rare Cancers (%)	Rare Cancers (%)
Yes	74	66
No	26	34

IF NO/NOT SURE: Which of the following would make you feel more in control of your cancer?	Non-Rare Cancers (%)	Rare Cancers (%)
Open discussion about my cancer and treatment options with my doctors and medical team	24	<b>18</b>
Becoming an advocate for my own health by searching out information and opinions	13	11
Knowing where to turn for credible and reliable information	13	10
Having access to professional to discuss the psychological dimensions of cancer	12	16
Greater knowledge and expertise with my doctor and medical team	11	13
Seeking out information about various treatment options	8	4
Information on clinical trials	7	9
Finding local support network and resources in my community	<b>6</b>	<b>12</b>
Access to second opinions	5	5
Finding support networks and resources online	2	3

**Q. Below is a list some cancer patients have said are reasons they feel in control of managing their cancer. Is each a major, a minor or not a reason you personally feel you are in control of your cancer? (Asked only of those who say they feel in control).**

Rare Cancer Patients

Information Source	Major Reason (%)	Minor Reason (%)	Not a Reason (%)	Not Sure (%)
I openly discuss my cancer and treatment options with my doctors and medical team.	92	4	3	1
I have become an advocate for my own health, searching out information and opinions.	88	8	3	1
My doctor and medical team has the necessary knowledge and expertise.	88	8	2	2
I know where to turn for credible and reliable information.	84	14	1	1
I have sought out information about various treatment options.	74	16	10	0
I have sought out second opinions.	49	25	25	1
I have found support networks and resources online.	40	30	29	1
I have sought out information on clinical trials.	33	29	34	4
I have access to professional to discuss the psychological dimensions of cancer.	33	31	33	3
I have found local support network and resources in my community.	32	22	43	3

Non-Rare Cancer Patients

Information Source	Major Reason (%)	Minor Reason (%)	Not a Reason (%)	Not Sure (%)
I openly discuss my cancer and treatment options with my doctors and medical team.	93	5	2	0
My doctor and medical team has the necessary knowledge and expertise.	92	6	2	0
I have become an advocate for my own health, searching out information and opinions.	84	12	4	0
I know where to turn for credible and reliable information.	84	14	1	1
I have sought out information about various treatment options.	68	21	10	1
I have sought out second opinions.	41	23	34	2
I have access to professional to discuss the psychological dimensions of cancer.	34	26	35	5
I have found support networks and resources online.	29	37	32	2
I have sought out information on clinical trials.	27	28	42	3
I have found local support network and resources in my community.	25	26	46	3

## 9. One Doctor versus Multidisciplinary Approach

Which one of the following best describes your treatment experience with cancer?	Non-Rare Cancers (%)	Rare Cancers (%)
I rely on the advice and counsel of several physicians who are part of my multidisciplinary team (including Surgeon, Pathologist, Hematologist, Oncologist, Radiologist)	67	72
I rely mainly on the advice and counsel of one doctor	32	26
Not sure	1	2

IF ONE DOCTOR: Do you know if the doctor you see most is speaking with or seeking advice from other physicians about your treatment?	Non-Rare Cancers (%)	Rare Cancers (%)
Yes	41	41
No	19	27
Not sure	40	32

Does knowing that your doctor seeks advice and counsel from other physicians make you feel better about your cancer treatment?	Non-Rare Cancers (%)	Rare Cancers (%)
Yes	96	100
No	0	0
Not sure	1	0
Other	3	0

IF DOCTOR NOT TALKING TO OTHERS: Would knowing that your doctor seeks advice and counsel from other physicians make you feel better about your cancer treatment?	Non-Rare Cancers (%)	Rare Cancers (%)
Yes	86	90
No	6	5
Not sure	8	5

Have you ever specifically asked the doctor you see most if he or she is speaking with or seeking advice from other physicians about your treatment?	Non-Rare Cancers (%)	Rare Cancers (%)
Yes	31	58
No	67	42
Not sure	2	0

<b>In your view, how important is it that cancer patients ask the doctor they see most if they are seeking advice from other physicians about treatment management?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Very important	<b>40</b>	<b>58</b>
Somewhat important	<b>40</b>	<b>26</b>
Not very important	14	11
Not at all important	2	0
Not sure	4	5

<b>Would the opportunity to work and communicate with a team of health professionals make you feel more confident about your cancer?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Yes	<b>67</b>	<b>87</b>
No	<b>13</b>	<b>8</b>
Not sure	<b>20</b>	<b>5</b>

<b>Which of the following are members of your multidisciplinary team?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Medical Oncologist	61	60
Surgeon	<b>53</b>	<b>47</b>
Radiologist	<b>37</b>	<b>47</b>
Radiation Oncologist	41	38
Nationally known expert in the field	<b>13</b>	<b>33</b>
Hematologist	<b>19</b>	<b>31</b>
Pathologist	27	27
Colleagues within the same practice or hospital	19	23
Other	10	10
Expert in the field who lives nearby	5	9

<b>Does having access to the advice and counsel of a multidisciplinary team of physicians make you feel better about your cancer treatment?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Yes	95	96
No	2	1
Not sure	3	3

<b>Does the fact that you work and communicate with a team of health professionals make you feel more in control in of your cancer?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Yes	92	91
No	4	5
Not sure	4	4

<b>Thinking about the physician you see most for treatment, do you know approximately how many other patients with your type of cancer he or she treats</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
Yes	<b>28</b>	<b>44</b>
No	<b>55</b>	<b>42</b>
Not sure	17	14

<b>Which one the following best describes your views about the number of other patients with your type of cancer that your doctor treats?</b>	<b>Non-Rare Cancers (%)</b>	<b>Rare Cancers (%)</b>
I want my doctor treating numerous other patients with my type of cancer.	<b>76</b>	<b>69</b>
I want my doctor treating several other patients with my type of cancer.	13	17
I want my doctor treating only a few other patients with my type of cancer.	0	0
Not sure	11	14