

Low-Grade Serous Ovarian Cancer (LGSOC) Patient Impact Survey Research Findings

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Background and Objectives

- Low-grade serous ovarian cancer (LGSOC) is a rare form of ovarian cancer that has recently been classified separately from the more common high-grade serous ovarian cancer (HGSOC). This rare form of ovarian cancer has a different epidemiology, pathology, clinical presentation, and outcomes which require a tailored approach to treatment and management.
- In order to better understand the experiences of this unique patient population, leaders in the LGSOC medical and advocacy community, along with Verastem Oncology, partnered to develop a first-of-its-kind, multi-national survey about the attitudes and behaviors of LGSOC* patients.
- Broadly, the 15-minute online survey assessed patient knowledge, burden and impact of disease, and barriers to treatment. With this information, healthcare providers, patient support groups, and the larger healthcare community will be able to better serve those living with this condition.
- Specific research objectives include:
 - Measure patient knowledge and understanding of their disease (LGSOC)
 - Illuminate the mental, emotional, and physical health impacts of living with LGSOC
 - Assess the economic burden of living with LGSOC
 - Identify key barriers to disease management

*For the purposes of this survey, the term LGSOC refers to people diagnosed with low-grade serous carcinoma of the ovary or peritoneum (the thin layer of tissue lining the abdomen).

Patient Survey Research Method

**Audience:**

186 women 18+ who have been diagnosed by a healthcare professional with low-grade serous ovarian cancer (LGSOC)

**Global Reach:**

Surveys were completed across the U.S. (106), U.K. (33), Canada (15), New Zealand (8), Australia (8), France (1), Italy (1), Spain (1), Germany (1), and other countries (12)

**Survey Timing:**

July 31 – August 29, 2023

**Mode:**

15-minute online survey

**Weighting:**

Data are not weighted and only represent the individuals who took this survey

Method Statement:

The patient survey was conducted online by The Harris Poll on behalf of Verastem Oncology among 186 women ages 18+ who have been diagnosed with low-grade serous ovarian cancer across 10+ countries: U.S. (n=106), UK (n=33), Canada (n=15), Australia (n=8), New Zealand (n=8), France (n=1), Germany (n=1), Italy (n=1), Spain (n=1), and other (n=12). The survey was conducted July 31st-August 29th 2023. Survey respondents for the patient survey were recruited from a mix of patient advocacy groups (Cure Our Ovarian Cancer, STAAR Ovarian Cancer Foundation), and Verastem Oncology social media, email, newsletters, and websites. Raw data were not weighted and are therefore only representative of the individuals who completed the survey. All women provided written agreement to participate and were not paid for their participation in the survey.

The sampling precision of Harris online polls is measured by using a Bayesian credible interval. For this study, the sample data is accurate to within ± 7.1 percentage points using a 95% confidence level. This credible interval will be wider among subsets of the surveyed population of interest.

All sample surveys and polls, whether or not they use probability sampling, are subject to other multiple sources of error which are most often not possible to quantify or estimate, including, but not limited to coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments.

Qualitative Interviews Research Method



Audience:

7 women 18+ who have been diagnosed by a healthcare professional with low-grade serous ovarian cancer (LGSOC)



Interview Timing:

August 29 – September 4, 2023



Mode:

60-minute web-assisted one-on-one (1:1) in-depth interviews (IDIs)



Weighting:

Data are not weighted, and the opinions and experiences expressed only represent those of each individual interviewed

- Participants for the qualitative interviews were recruited via an LGSOC patient advocacy group leader who was involved in the steering committee that designed this research.
- All women provided written and verbal agreement to participate in the interview and have their video and audio from the interview included in a video highlights reel and were not paid for their participation.
- The opinions and experiences expressed in the interviews and in the video highlights reel are not representative in any way, and only represent those of each individual who participated. All qualitative findings should be interpreted with caution and as directional only.
- n=6 women were from the U.S., and n=1 was from the U.K.
- None of the women who participated in the interviews were currently enrolled in a Verastem Oncology-sponsored clinical trial.

Report Notes

In tables and charts:

- Percentages may not add up to 100% due to weighting, computer rounding, and/or the acceptance of multiple responses.
- An asterisk (*) in a data chart indicates a percentage greater than zero but less than 1%; a “ – ” indicates a value of zero.
- Results based on small samples ($n < 100$) are too small to report quantitatively and should be interpreted as directional only. These are noted with “*Caution, small base ($n < 100$).”

Throughout this report:

- We have included findings among subgroups with statistically significant differences at the 95% confidence interval where findings were compelling or of particular note and sample sizes were large enough for analysis ($n \geq 30$). Look for the yellow text boxes (below) to denote these call outs. Supporting data for these call outs may be placed in notes section.

Subgroup finding of interest

- Throughout the patient detailed findings, we have included directional qualitative findings and/or quotes with the icons/formats below:



Qualitative directional finding or quote

- We may refer to low-grade serous ovarian cancer as “LGSOC”, to high-grade serous ovarian cancer as “HGSOC”, to treatment(s) as “Tx(s),” , to diagnosis as “Dx”, to health care provider as “HCP,” and/or to quality of life as “QOL” for brevity.
- Base labels, sizes, and question text are included within the notes section of each page for reference.

Key Findings

Key Findings: Knowledge and Resources

Prior to diagnosis, there is virtually no awareness of LGSOC and there remains some confusion or misunderstanding around LGSOC vs. HGSOC and that LGSOC affects younger women more so than other ovarian cancers. This underscores the importance of additional education for HCPs, especially generalists who may be less aware or familiar, but often first to see patients based on symptoms.

- Nearly all women with LGSOC (99%) had never heard of the condition before they were diagnosed and 65% agree that if they had known more about LGSOC, they probably would have been diagnosed sooner.
- Even among patients, there is some confusion over the seriousness of LGSOC vs. HGSOC – 4 in 10 (40%) don't know that LGSOC is NOT a less severe form of ovarian cancer vs. HGSOC. And, more than 1 in 4 patients (27%) don't know that LGSOC can affect younger people more so than other forms of ovarian cancer.
- 88% *strongly* agree that they wish more attention was paid to LGSOC as its own distinct disease.
- While 3 in 4 (75%) feel the HCP who diagnosed them with LGSOC was knowledgeable, only 2 in 5 (40%) feel they were very knowledgeable. Those diagnosed by an Oncologist are more likely to say their HCP was knowledgeable (85% vs. 60%* diagnosed by OBGYN/PCP) and are twice as likely to say they were *very* knowledgeable (50% vs. 23%*); they are also more likely to feel their HCP did a good job explaining LGSOC and answering questions (76% vs. 53%*).
- Those who say their HCP is very knowledgeable* are more likely to say their path to diagnosis was easy, are more likely to be satisfied with how long it took to be diagnosed, and are less likely to *strongly* agree that their path to diagnosis was frustrating. In addition, they are more likely to say it was very easy to access treatment.
- Qualitatively, some women feel generalists who are often the “first line” HCP seen for many of the common but vague LGSOC symptoms need to know more about LGSOC and its’ symptoms to better be able to suspect possible LGSOC and promptly refer patients to a Gynecological Oncologist.

Key Findings: Disease Management and Barriers

Several years often pass from the time a woman with LGSOC starts experiencing symptoms to when she ultimately receives a diagnosis, a process that most women find difficult and frustrating. Patients report that HCPs often dismiss or misdiagnose symptoms, resulting in women being bounced around to multiple types of doctors and having to advocate for themselves and really listen to their bodies. A lack of treatment options and the difficulty of dealing with side effects, coupled with the anxiety and worry of having to live with uncertainty, make many women feel like their lives revolve around their cancer.

- Among the 81% who experienced symptoms, an average of nearly 3 years passed before they ultimately received a diagnosis. Nearly 3 in 4 (72%) wish they had paid closer attention to their body and sought medical attention sooner than they did.
 - Only 2 in 5 (41%) are satisfied with how long it took to be diagnosed and more than 2 in 3 found their path to LGSOC diagnosis difficult (73%) or frustrating (68%).
 - 68% of those who experienced symptoms report that their HCP attributed their symptoms to another health condition and 66% agree that, before they were diagnosed with LGSOC, they felt their symptoms were dismissed by their HCP.
 - In fact, the two biggest things LGSOC patients want women to know about it are that symptoms can be easily misdiagnosed as something else (87%) and it's important to listen to your body and seek medical attention as soon as possible (82%).
- Living with uncertainty (68%), limited treatment options (60%), and treatment side effects (52%) are the biggest challenges women with LGSOC face in managing their condition. Other challenges include anxiety and worry (48%) and feeling like their lives revolve around their cancer (41%).
 - Less than 1 in 3 (28%) are satisfied with available treatment options and the vast majority (90%) feel LGSOC patients get treatment leftovers.
 - 1 in 4 (25%) ever stopped or paused their treatments because they couldn't tolerate the side effects.

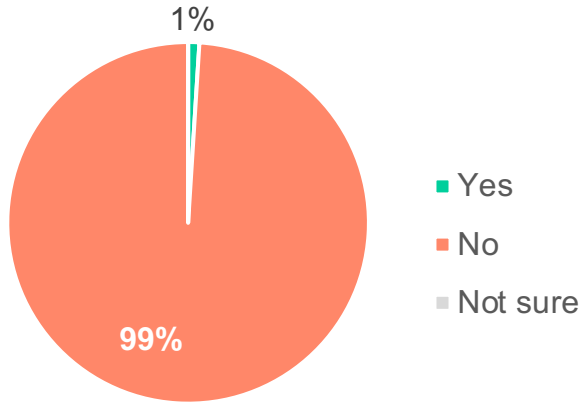
Detailed Findings

Knowledge and Resources

Virtually all LGSOC patients had never heard of the condition before being diagnosed

Two-thirds agree that if they had known more about LGSOC, they probably would have been diagnosed sooner

LGSOC Awareness Before Diagnosis

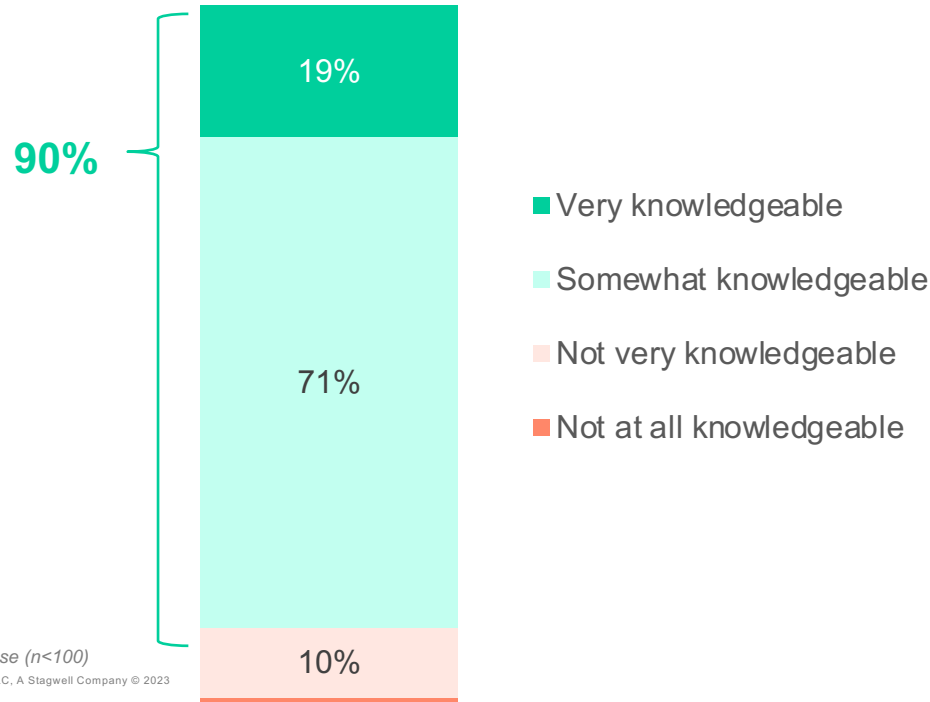


"I never even heard of it before I had it, so it wasn't on my radar at all. And it became evident, it's not on doctors' radars either. GPs, or consultants, even. So ovarian cancer, I think, is one of those ones that nobody really thinks about." – Alex, U.K.

While a majority feel knowledgeable about their condition, less than 1 in 5 feel *very* knowledgeable

And, 9 in 10 feel that having more information would make them feel more confident in managing it

Overall Knowledge of LGSOC



*Caution: small base (n<100)

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This is especially true for those more recently diagnosed (95%* diagnosed within the last 2 years agree vs. 86% 3+ years)

The majority of patients know that LGSOC isn't often responsive to chemo, that recurrence is common, and that it can be difficult to diagnose

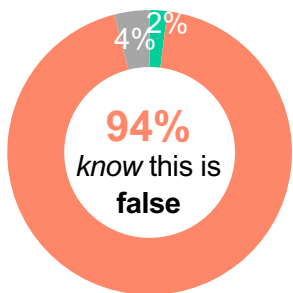
However, more than 1 in 4 aren't sure or don't know that LGSOC can affect younger people more so than other ovarian cancers



Knowledge Of LGSOC Specifics

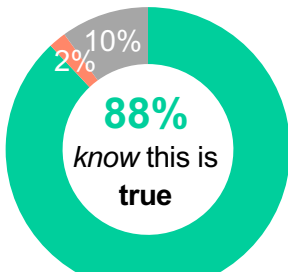
FALSE

LGSOC is often quite responsive to chemotherapy.



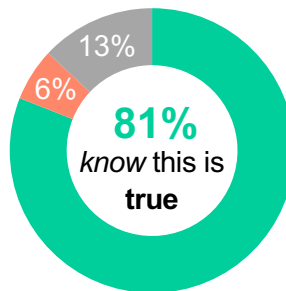
TRUE

Most women with LGSOC will have their cancer come back (recur).



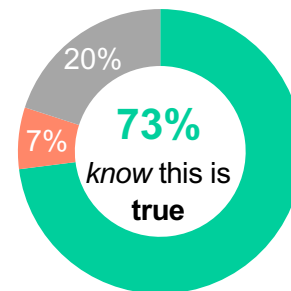
TRUE

LGSOC can be difficult to diagnose because symptoms are similar to other cancers or diseases/disorders.



TRUE

LGSOC can affect younger people more so than other forms of ovarian cancer.



Those diagnosed by an Oncologist are more likely to know this is true (92% vs. 77%* diagnosed by OBGYN/PCP)

*Caution: small base (n<100)
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Qualitative Findings



Knowledge Of LGSOC Specifics

Effectiveness of Chemotherapy

- A few women discuss the challenges associated with deciding whether to undergo chemotherapy or not based on their knowledge and understanding of its efficacy for this specific type of ovarian cancer, despite chemotherapy being one of the preferred treatment options for this disease.



The big question with this cancer is, to chemo or not to chemo? And that's huge. It's the question of do you go right to the aromatase inhibitor of letrozole? Or do you do your six rounds of carboplatin chemo and then to the aromatase inhibitor? And they just don't have the data yet, and the numbers to make a recommendation either way. They can say, "This is the standard of care" and I've heard that so many times... But there is so much evidence out there increasingly that the aromatase inhibitors are working just as well, maybe if not more than the chemo too. – Emma, U.S



Risk of Recurrence

- Several women un-prompted mention the high rate of recurrence, indicating it is top of mind and well-known. However, one patient initially diagnosed by a Gynecologist was told if she was “free and clear for 5 years, you should be good,” but once she met with a Gynecological Oncologist several years later, he explained the high rate of recurrence.



I went by what my doctor [GYN] said, and he at the time said that as long as we are free and clear for five years... They would do tests and stuff... then I should be good to go; I shouldn't have cancer anymore.... And that's what in my mind I kept. But then I moved out of state...so I had to find a new doctor [GYN ONC]... He is the one that actually told me that I was not free and clear and that 90% chance that it would come back in my lifetime. So he broke my heart, obviously, because here I was thinking I was three years in and I was doing good, but he opened my eyes to, "Okay, I'm not done with this." - Deana, U.S.



Qualitative Findings



Knowledge Of LGSOC Specifics, Continued

Difficult to Diagnose

- Many of the women interviewed describe how difficult this condition is to diagnose because symptoms are similar to other cancers or diseases/disorders, as many of them experienced this themselves. Most women's symptoms were misattributed to various gastrointestinal diseases (often IBS), poor diet/weight, age, cysts, even birth control side effects, etc.

“ So I went to about five different gastroenterologists, bounced around over those probably for another two years, trying different diets, trying different medication for IBS. It was a lot of, a lot of people have this and you're too young for it to be anything serious and blood work looks good....So there was these GI symptoms for quite a while and then it started to get more symptoms. So I would say probably by early 2020, a year before my diagnosis was when I really started to notice the other symptoms, urgency to pee ...And I went to my gynecologist and they said, "Seems like a gastro issue." And the gastro said, "Seems like a gynecological issue." And I kind of got passed back and forth. – Ellie, U.S.



Affects Younger Women

- Several of the women interviewed were diagnosed at a young age (under 40) so this was very relevant and top of mind for them, but not something they knew **before** being diagnosed. They stress the importance of HCPs knowing this, as many of them were dismissed as being too young for their symptoms to be cancer.

“ There's no such thing as being too young for cancer, first of all. We have this idea of what ovarian cancer looks like and that it's our grandma's, and that's just not the case. Ovarian cancer looks like me. – Emma, diagnosed at 26

Along the journey of getting my diagnosis, my obstetrician gynecologist continued to tell me, "Oh, Connie, you don't have cancer. You're too young." – Connie, diagnosed at 36

I was diagnosed at the age of 29 with low grade ovarian cancer. It wasn't till about two years where I was officially diagnosed with ovarian cancer. I definitely think that my age had a huge, significant impact on why I was diagnosed later. – Tiffany, diagnosed at 29



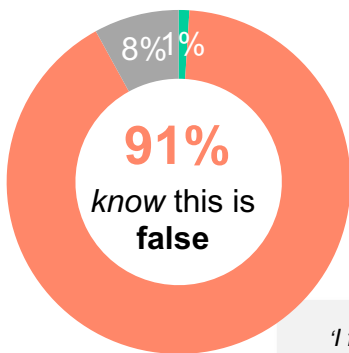
While most know LGSOC doesn't grow/spread at similar rates as HGSOC, fewer know that LGSOC isn't less severe than HGSOC and ~1 in 4 incorrectly believe it is

Despite this, ~9 in 10 feel they have a good understanding of the differences between LGSOC and HGSOC, though few feel strongly

Knowledge of LGSOC vs. HGSOC

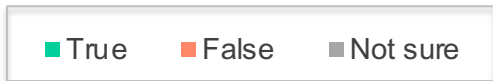
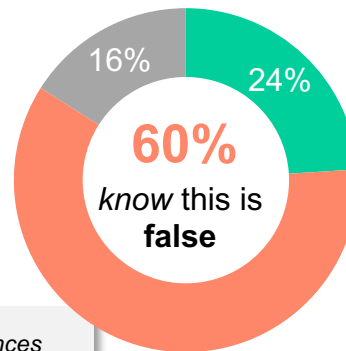
FALSE

LGSOC usually grows and spreads at similar rates to HGSOC.



FALSE

LGSOC is a less severe form of ovarian cancer compared to HGSOC.



'I feel that I have a good understanding of the differences between low-grade serous ovarian cancer (LGSOC) and high-grade serous ovarian cancer (HGSOC).'



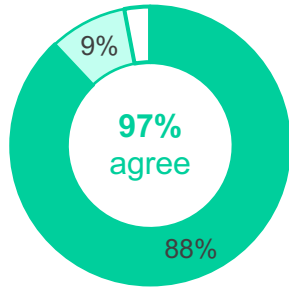
Those living outside of the U.S. are more likely to agree (94%* vs. 81% U.S.)

*Caution: small base (n<100)
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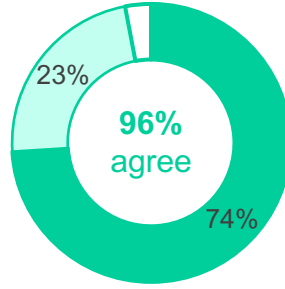
A majority of patients feel strongly that most people have no idea that LGSOC is its own distinct disease, including that not enough HCPs recognize it as such

Nearly 9 in 10 *strongly* agree that they wish more attention was paid to LGSOC as its own distinct disease

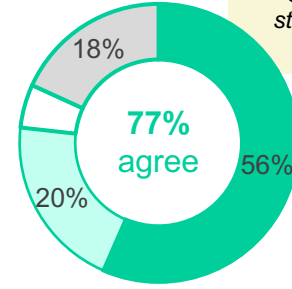
Attitudes About LGSOC As Its Own Distinct Disease



'I wish more attention was paid to LGSOC as its own distinct disease.'



'Most people have no idea that low-grade serous ovarian cancer (LGSOC) is a distinct disease.'



'Not enough healthcare providers recognize LGSOC as its own distinct disease.'

Those living outside of the U.S. are more likely to *strongly* agree (65%* vs. 50% U.S.)

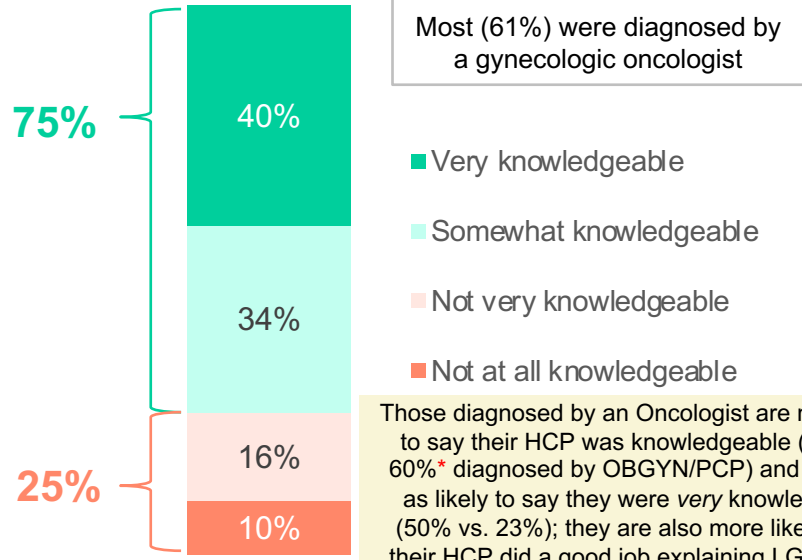
■ Strongly agree
 ■ Somewhat agree
 ■ Strongly/somewhat disagree
 ■ Not sure

*Caution: small base (n<100)

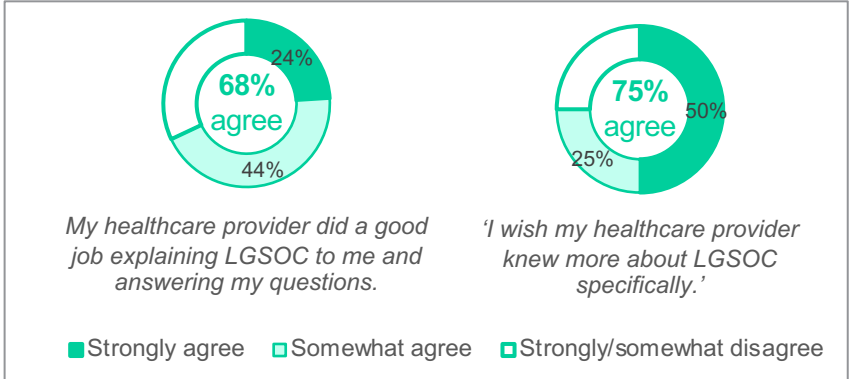
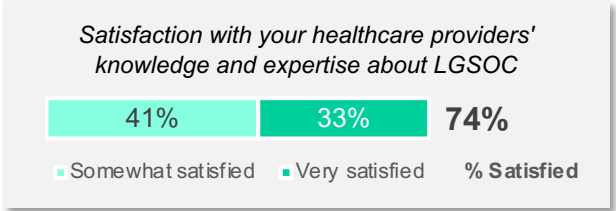
While most say their HCP was knowledgeable about LGSOC and are satisfied with their expertise, only ~1 in 3 or less feel *strongly* satisfied or *strongly* agree that their HCP did a good job explaining LGSOC

And, a majority, including half who *strongly* agree, wish their HCP knew more about LGSOC specifically

HCP Knowledge About LGSOC



Those diagnosed by an Oncologist are more likely to say their HCP was knowledgeable (85% vs. 60%* diagnosed by OBGYN/PCP) and are twice as likely to say they were very knowledgeable (50% vs. 23%); they are also more likely to feel their HCP did a good job explaining LGSOC and answering questions (76% vs. 53%)



*Caution: small base (n<100)
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Qualitative Findings



HCP Knowledge About LGSOC

- Women are split on whether they found their HCP(s) to be very knowledgeable; some did and some didn't, and it often depends on the medical specialty, with generalists typically being less knowledgeable and Gynecological Oncologists most knowledgeable, as also evidenced in the quantitative findings.
- However, a few women recognize that any knowledge gaps may not necessarily be a deficiency of the HCPs themselves, and rather a function of the condition being rare, under-studied, and under-funded. These women felt their HCP was as knowledgeable as they could be, but that generally there is a lack of information on the condition in the scientific community.
- A few mention how important it is that the HCP be knowledgeable as it instills a sense of confidence, comfort, safety, and hope.
- Given the nature of the symptoms LGSOC can present with, women feel it is important that generalists who are often the “first line” HCP seen for many of the common but vague LGSOC symptoms (bloating, abdominal/back pain, fatigue, frequent/urgent need to pee, etc.) know about LGSOC and its' symptoms to better be able to suspect possible LGSOC and promptly refer patients to a Gynecological Oncologist.



I think when you think about general medical providers, like regular gynecologists, primary care physicians need more education on the symptoms of ovarian cancer and the fact that anyone of any age can be diagnosed with it. – Ellie, U.S.

From the first time I sat down with him, I immediately thought he is the smartest person I've ever met... He explained a lot of things, spent a lot of time with us because I was so confused, and he really made me feel comfortable like I'm not going to die...I felt hope, I felt a lot of comfort and confidence in it. – Deana, U.S.



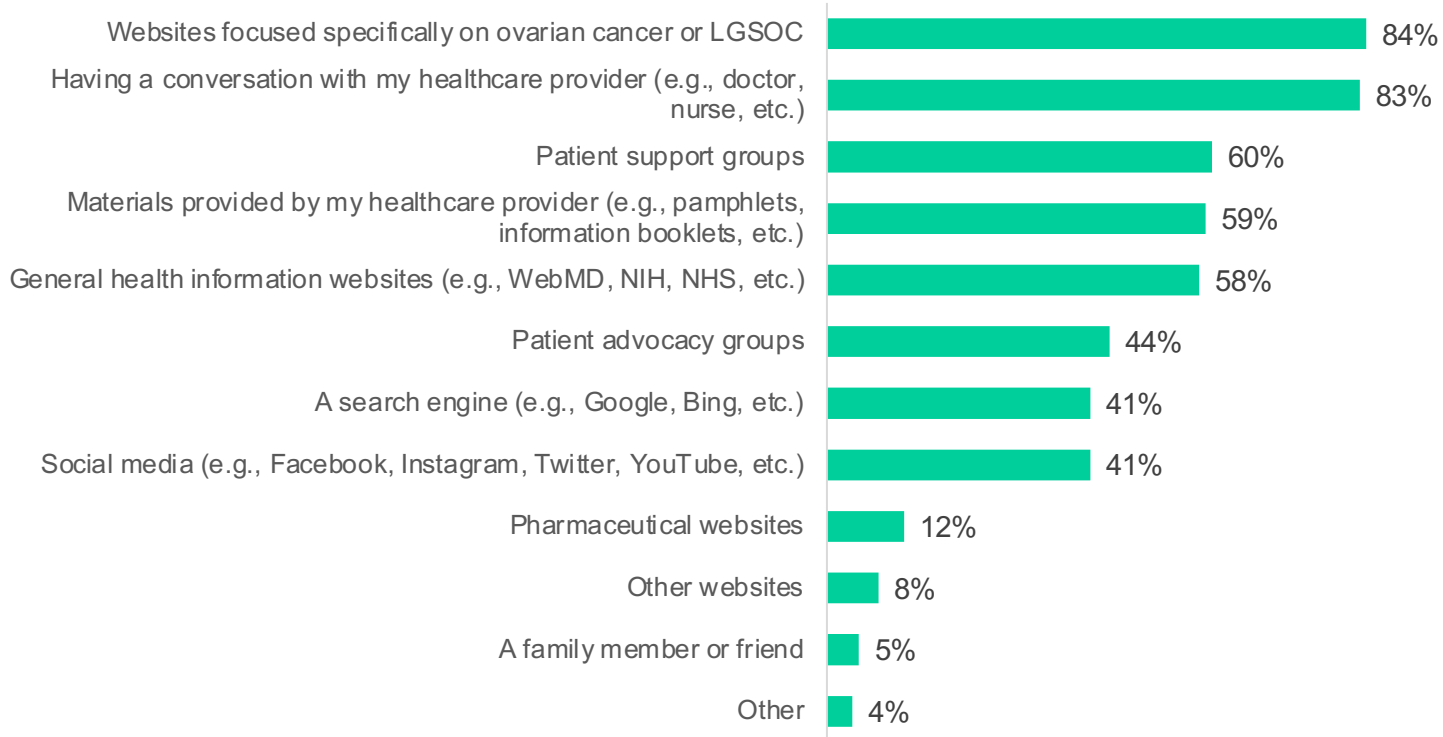
I think that as a whole, we don't know enough about the disease... Low grade serous ovarian cancer is so rare that it's just completely understudied...medical oncologists and researchers have a lot more work to do...there's just so much more to learn about what causes it, what treatments could be effective, and how to support people who live with it. – Ellie, U.S.



The most preferred LGSOC information sources are ovarian or LGSOC specific websites and HCP discussions

Many also prefer to receive LGSOC information from patient support groups, HCP provided materials, and general health websites

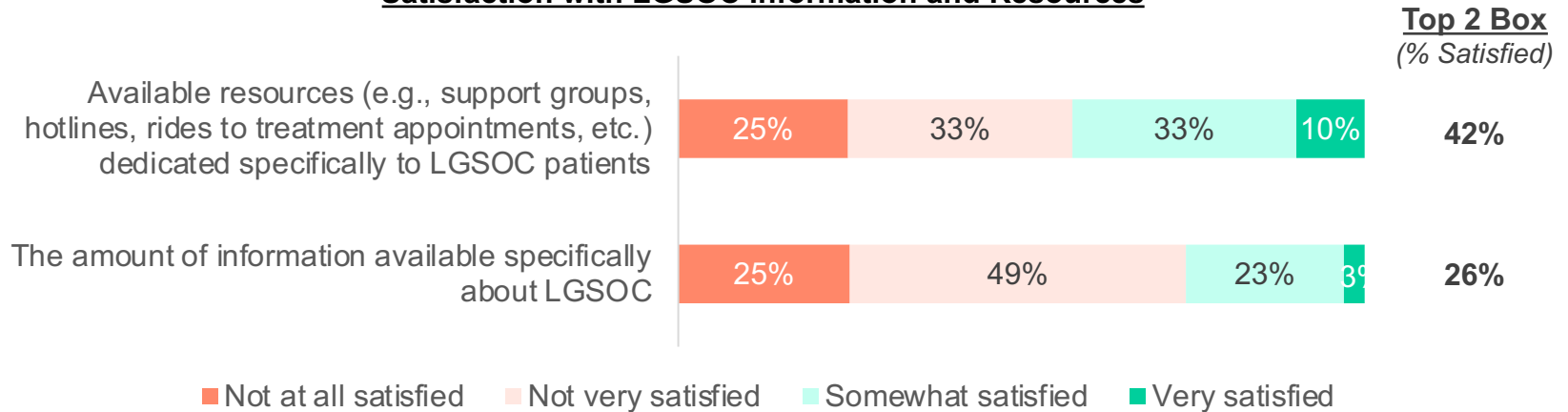
Preferred Sources of LGSOC Information



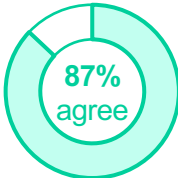
Only ~2 in 5 are satisfied with available resources dedicated to LGSOC patients and only ~1 in 4 are satisfied with the amount of LGSOC information available

And, nearly 9 in 10 wish there were more resources dedicated specifically to LGSOC patients

Satisfaction with LGSOC Information and Resources



I think there is a whole lot of information on high grade serous ovarian cancer, which makes up 80% of ovarian cancer diagnoses. Low grade, on the other hand, makes up less than 10% of all ovarian cancer diagnoses, and there is not nearly enough information out there for women who are trying to figure out potential symptoms, what to expect, that is targeted towards patients with low grade. I've been very, very disappointed in that. – Connie, U.S.

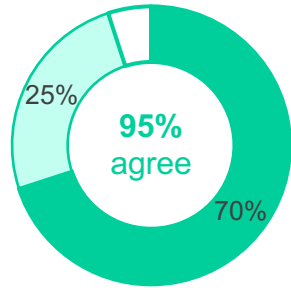


I wish there were more resources (e.g., support groups, hotlines, rides to treatment appointments, etc.) dedicated specifically to LGSOC patients.

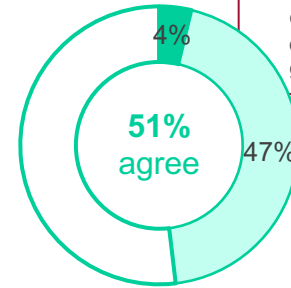
Most patients feel strongly that there's rarely mention of LGSOC in ovarian cancer information, and only around half feel LGSOC information is easy to understand

Very few feel strongly that information about LGSOC is easy to understand

Attitudes About LGSOC Information



'While there is a lot of information about ovarian cancer, there's rarely mention of LGSOC specifically.'



'Information about LGSOC is easy to understand.'

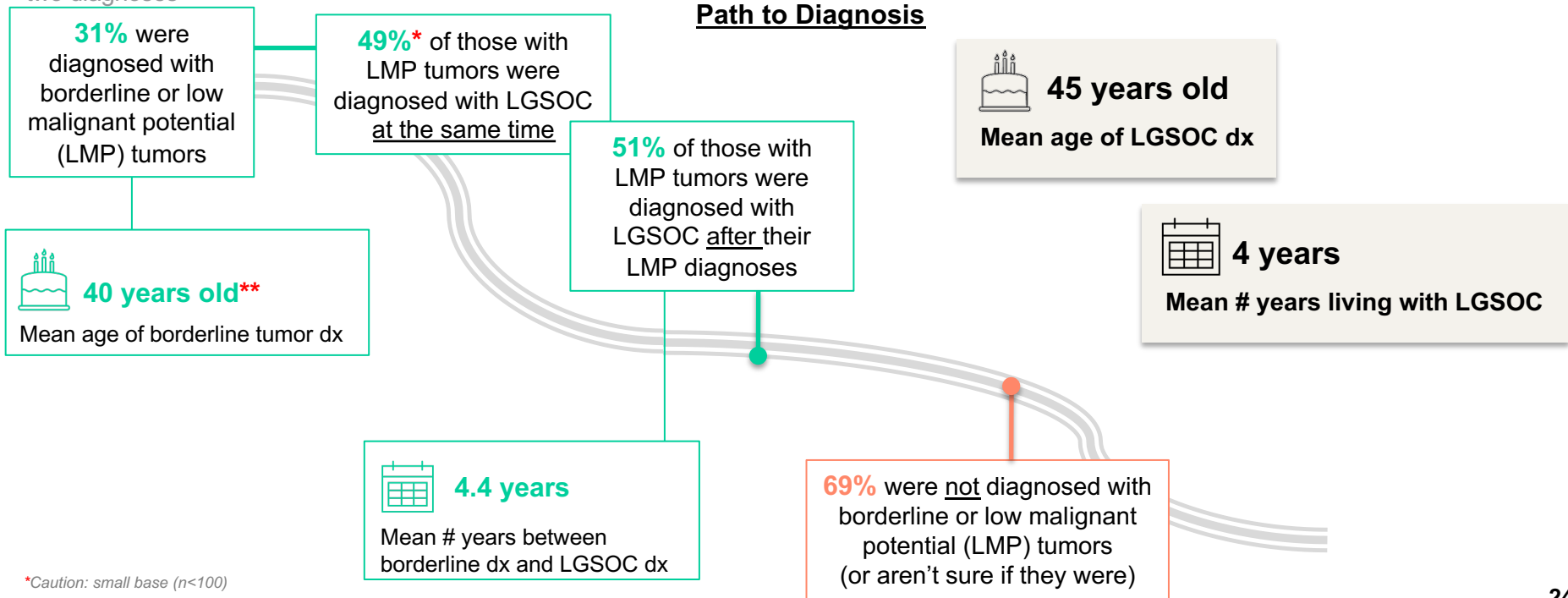


When my doctor diagnosed me, I had a hard time understanding him when it came to exactly what it was...So I felt like I had five eyes and was so confused as to what was going on in the beginning... – Tiffany, U.S.

■ Strongly agree ■ Somewhat agree ■ Strongly/somewhat disagree

3 in 10 LGSOC patients have had a low malignant potential (LMP) tumor diagnosis, ~half of whom were first diagnosed with the tumor and later diagnosed with LGSOC

On average, women are diagnosed with LGSOC at 45 years old, and those who had an LMP diagnosis went more than 4 years between the two diagnoses



*Caution: small base (n<100)

**Caution: very small base (n<30)

Disease Management and Barriers

Among the 8 in 10 who experienced symptoms, an average of nearly 3 years passed before they ultimately received a diagnosis

For 2 in 3, once they reported symptoms, an LGSOC diagnosis was made within 6 months, but most women wish they had paid closer attention to their body and sought medical attention sooner

Path to Diagnosis Based on Symptoms

Among those who experienced symptoms

81% experienced symptoms



1.7 years

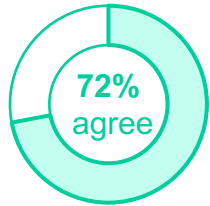
Mean time from first experienced symptoms to reported them to an HCP
(Median: 1 year)



1.2 years

Mean time from first reported symptoms to an HCP to received LGSOC diagnosis
(Median: 4 months)

63% say it took 6 months or less



'I wish I had paid closer attention to my body and sought medical attention sooner than I did.'

% Strongly/Somewhat agree

*Caution: small base (n<100)

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Those living outside of the U.S. report a longer average time to diagnosis once symptoms were reported to an HCP (1.6 years* vs. ~10 ½ months* U.S.)

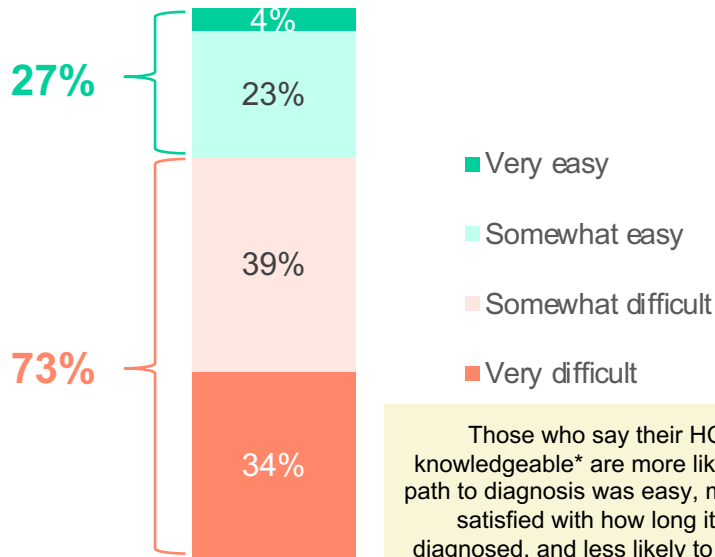
2.9 years
Mean time from first experienced symptoms to received a diagnosis
(Median: 1.5 years)

Only 2 in 5 are satisfied with how long it took to be diagnosed and more than 2 in 3 found their path to LGSOC diagnosis difficult or frustrating

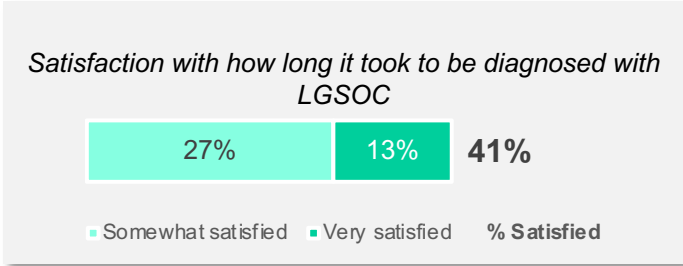
Less than 1 in 5 were *very* satisfied with how long their diagnosis took, and almost none felt it was *very* easy

Experience with Path to Diagnosis

How Easy or Difficult Was Path to LGSOC Diagnosis



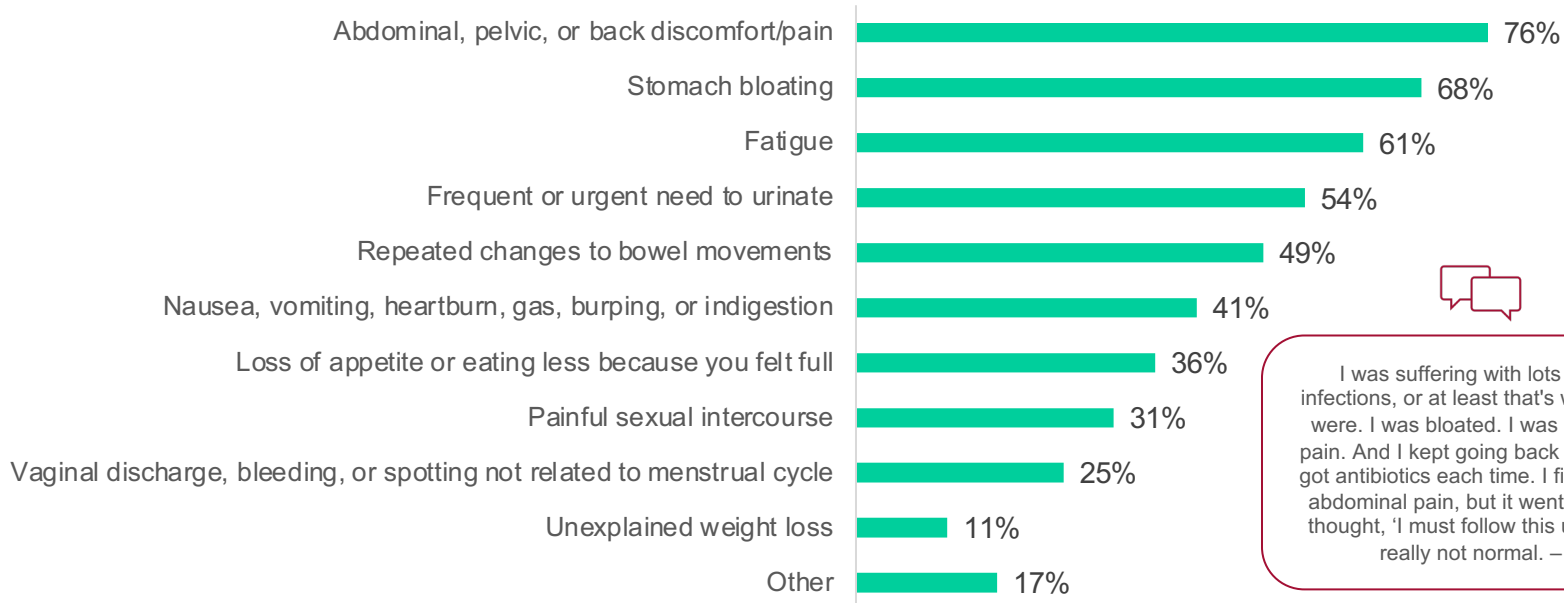
Those who say their HCP is very knowledgeable* are more likely to say their path to diagnosis was easy, more likely to be satisfied with how long it took to be diagnosed, and less likely to strongly agree that their path to diagnosis was frustrating



*Caution: small base (n<100)

The most common symptoms women experienced before their LGSOC diagnosis were abdominal or back pain, stomach bloating, fatigue, and frequent/urgent need to urinate

Symptoms Experienced
Among those who experienced symptoms



I was suffering with lots of urinary tract infections, or at least that's what I thought they were. I was bloated. I was having abdominal pain. And I kept going back to the GP, and just got antibiotics each time. I finally had such bad abdominal pain, but it went away again. But I thought, 'I must follow this up, because that's really not normal. – Alex, U.K.

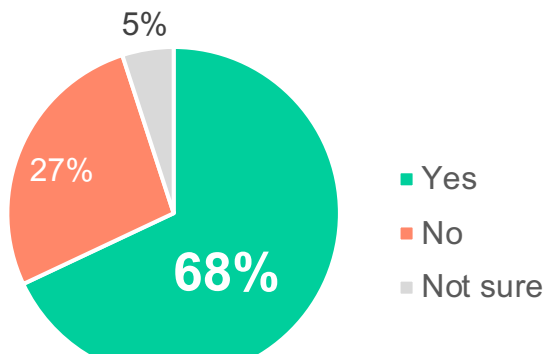
~2 in 3 who experienced symptoms say their HCP attributed them to another health condition or felt their symptoms were dismissed by their HCP

Younger women are more likely say their symptoms were misattributed or dismissed

Symptom Misdiagnosis and Dismissal

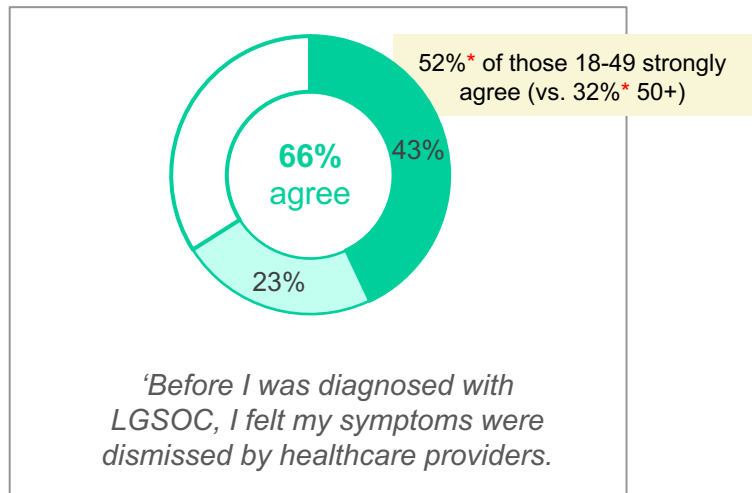
Among those who experienced symptoms

HCP Attributed Symptoms To Another Health Condition



77%* of those 18-49 say their HCP attributed symptoms to another health condition (vs. 56%* 50+)

Women mention having symptoms misattributed to conditions such as IBS, bowel/bladder cancer, gallstones, infections, and even birth control side effects



■ Strongly agree ■ Somewhat agree ■ Strongly/somewhat disagree

I couldn't understand why they said it shouldn't be all that uncomfortable, when actually, it was agony. – Alex, U.K.

Qualitative Findings



Path to Diagnosis & Symptom Misdiagnosis and Dismissal

- Several women experienced symptoms that often led them first to a general practitioner (GP or Gynecologist) who may have run some tests but more often than not had no answers and either told them to make diet/lifestyle changes or referred them to a Gastroenterologist or Gynecologist (or vice versa).
 - Common symptoms included abdominal pain (at times so severe it sent a couple of women to the ER), extreme bloating, and symptoms of a UTI.
- The time from symptom onset to diagnosis varied widely, anywhere from ~1 year to 10-15 years for one woman.
- A few of the younger women describe feeling less urgency or concern from HCPs given their age, though overall most women felt there was a lack of urgency or that HCPs didn't take their symptoms very seriously or they weren't being heard by their HCP(s).
- Many expressed frustration with their path to diagnosis given the bouncing around to various doctors, misdiagnoses, and dismissal of what they were going through.



If I could rewrite my journey to diagnosis, I wish that the physicians would have a sense of urgency when a patient comes in about the same thing over and over and over again. Everything just seemed to be dismissed and you're made to feel like it's either due to your weight or it's your age as a woman, you're entering menopause. – Tami, U.S.

Two and a half years. But at least like six to eight months of really debilitating symptoms to the point where it was really impacting my day to day and I was still not being believed. And it was still a lot of, change your diet, this, this, this. Kind of just, you have to deal with it. – Ellie, U.S.



"Hey, if you've got these symptoms for more than two weeks, bloating, more frequent urination, pelvic pain, menstrual irregularities, let's spread the word." We need to let women know to really be observant of their bodies and make sure that you're talking either to your primary care physician or your obstetrician gynecologist. And if you don't get the answer you want, if you want follow-up, if you want a second opinion, go seek it out. That's so, so important. – Connie, U.S.

The symptoms were getting worse but it seemed like I was being believed less and less almost. So they just put that blanket IBS diagnosis on it. – Ellie, U.S.

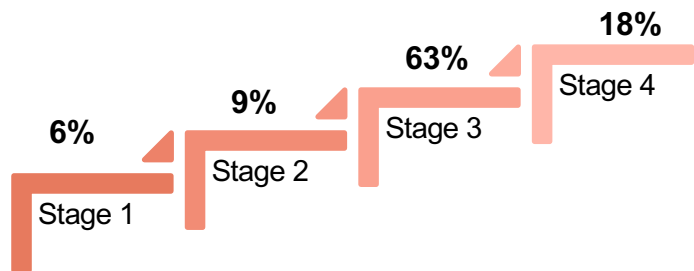


Most women were diagnosed at stage 3, ~half are currently in remission and most other patients are currently at stage 3 or 4

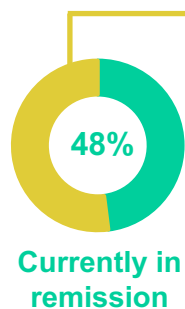
More than 1 in 3 have had their cancer recur and 3 in 10 aren't sure what their current stage is

Progression

Stage LGSOC Diagnosed At

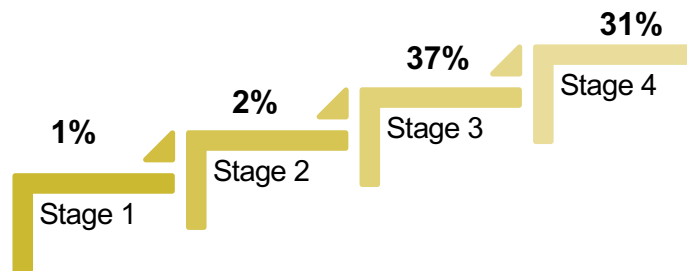


3% not sure/don't recall



Current Stage

Among those not currently in remission*



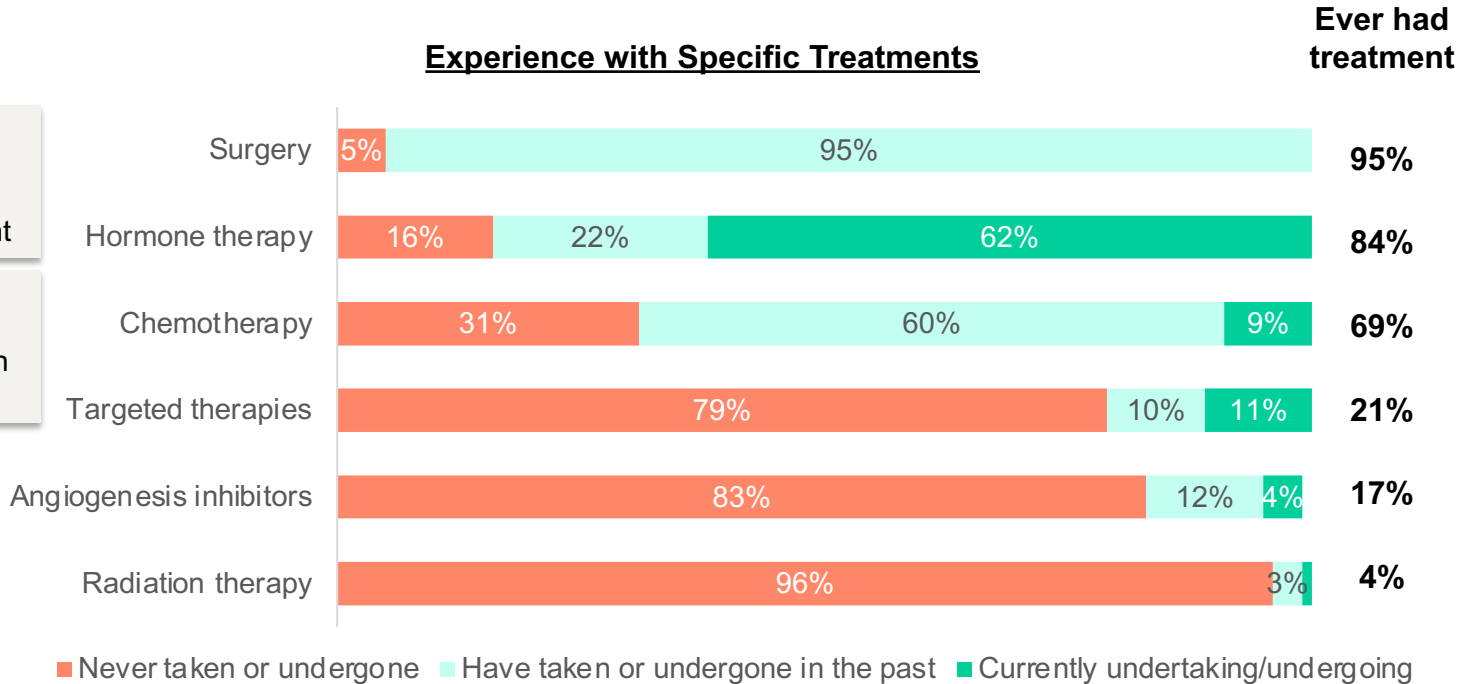
29% not sure

*Caution: small base (n<100)

~8 in 10 patients are currently on treatment, the most common being hormone therapy; ~7 in 10 have had chemotherapy but few are currently undergoing

100%
Have had some form of treatment

82%
Are **currently** on a treatment



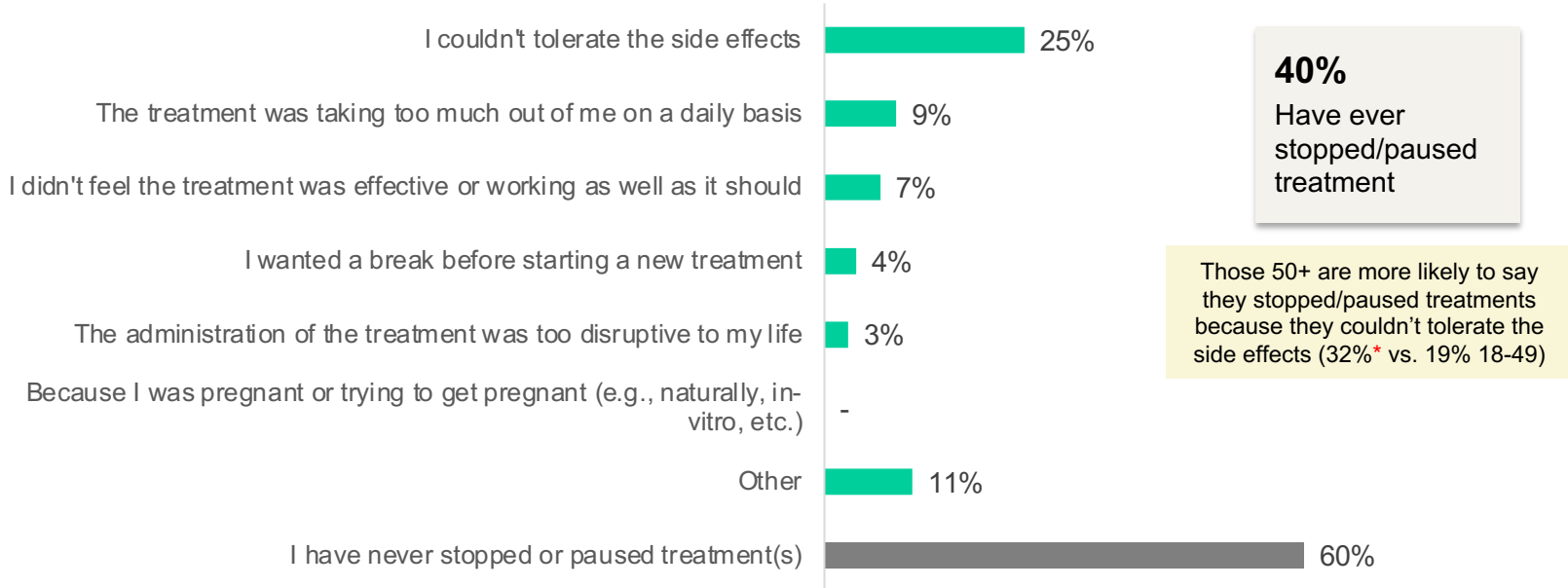
73%* of women in remission are currently taking hormone therapy

*Caution: small base (n<100) **32**

2 in 5 women with LGSOC have ever stopped or paused treatment, primarily because they couldn't tolerate the side effects

Stops or Pauses to Treatments

Among those who have ever undergone treatment

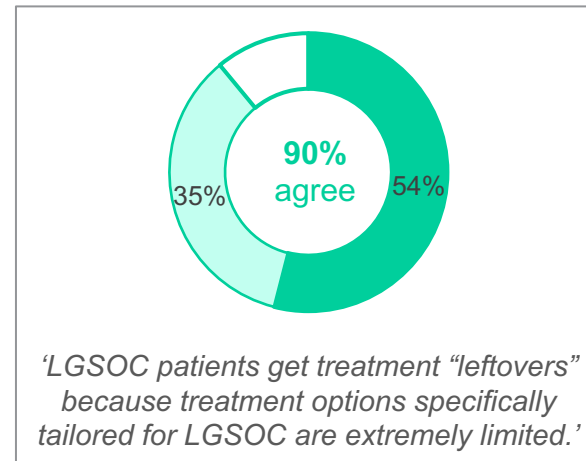
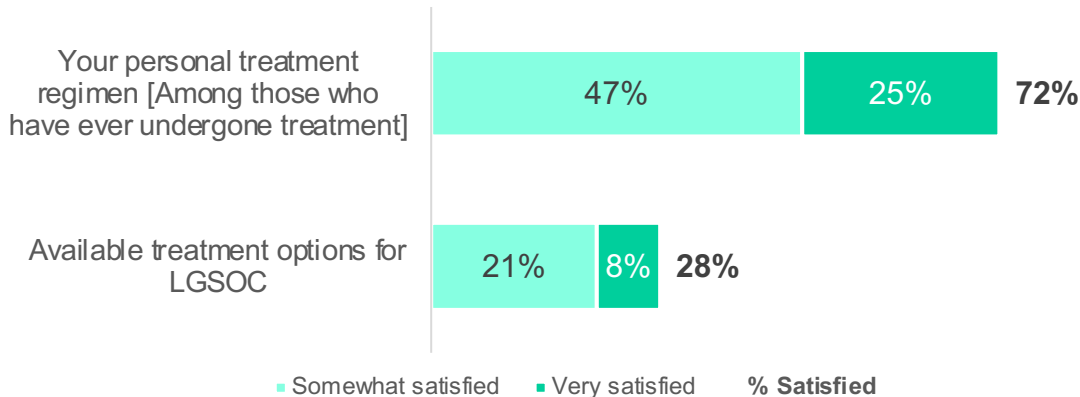


*Caution: small base (n<100)

Less than 1 in 3 are satisfied with available treatment options and the vast majority feel patients with LGSOC get “treatment leftovers”

Most are satisfied (though not *strongly*) with their *personal* treatment regimen

Satisfaction With Treatments



Legend: Strongly agree (dark teal), Somewhat agree (light teal), Strongly/somewhat disagree (medium teal)

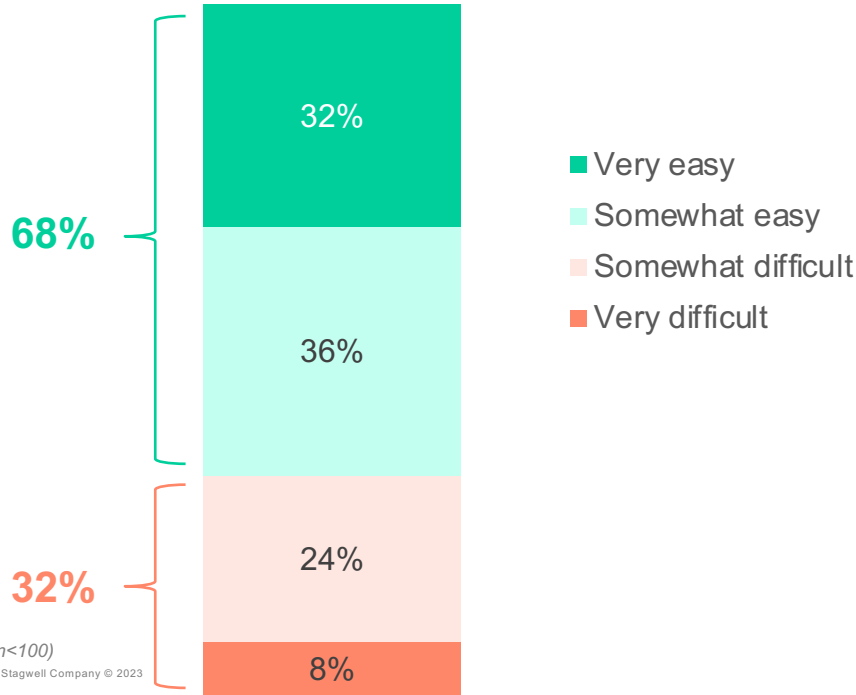
Those who live outside of the U.S. are more likely to *strongly* agree (65%* vs. 46%)

The medicine I'm taking, they literally passed the clinical trial in March, it's not even for ovarian cancer. It's actually specifically for metastatic breast cancer, but they found that it helps with metastatic ovarian cancer as well. It's like we don't even have our own treatment. We're using other diseases', other cancers', medicine to help us. Why don't we have a treatment for low-grade ovarian cancer? – Tiffany, U.S.

While most say it was easy to access all of the treatments they needed, only 1 in 3 feel it was *very easy* and those living outside of the U.S. had more difficulty

For these patients, the more knowledgeable the HCP, the easier the access to treatment

Access To Treatments



Those residing outside of the U.S. are more likely to say it is/was somewhat/very **difficult** to access all of the medical treatments they needed (41% vs. 25% U.S.)

Conversely, those living in the U.S. are more likely to say it was *very easy* (40% vs. 23% outside of the U.S.)

Those who feel their HCP is very knowledgeable are more likely to say it was *very easy* to access treatment (44%* vs. 24%)

*Caution: small base (n<100)
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Living with uncertainty, limited treatment options, and treatment side effects are the biggest challenges women with LGSOC face in managing their condition

Other challenges include anxiety and worry and a lack of information in general and among HCPs

Biggest Challenges In Managing LGSOC

Select up to 5

Top



68%

Living with uncertainty that my cancer may return



60%

Having limited treatment options available



52%

Dealing with treatment side effects

Others

48%



Feeling anxious or worried

41%



Feeling like my life revolves around my cancer

34%



Experiencing symptoms of menopause/perimenopause earlier than expected

27%



Healthcare providers not having enough knowledge about LGSOC

27%



Finding the right treatment regimen that works for me

25%



Not having enough information about LGSOC in general

Additional challenges <25% not shown, see notes

Qualitative Findings



Biggest Challenges In Managing LGSOC

- Most women find the uncertainty of living with LGSOC extremely challenging – whether the cancer will recur, how they will feel day to day, what the future may/may not hold, etc.
- Several talk about how they feel sometimes like their life now revolves around their cancer, particularly as it relates to monitoring scans (i.e., the anxiety women can feel as they approach their next scan) and the limitations that physical impairments have put on them.
- Many talk about the mental and physical health impacts as a result of the diagnosis itself and/or treatment side effects.

“ It's a matter of is it going to be here or not? Is this the time I'm going to come in and they're going to say, sorry, it's back. Or is this the time I get to go home and be like, okay, it's not this time, but maybe next time. So I went through several years and this was just probably five, six years ago, several years of every time I left the doctor's office, good or bad, I would cry. Because you're either really relieved or it's back again, what do I do? But you're relieved, but you're only relieved for three months, because in three months it could be here again. – Deana, U.S.

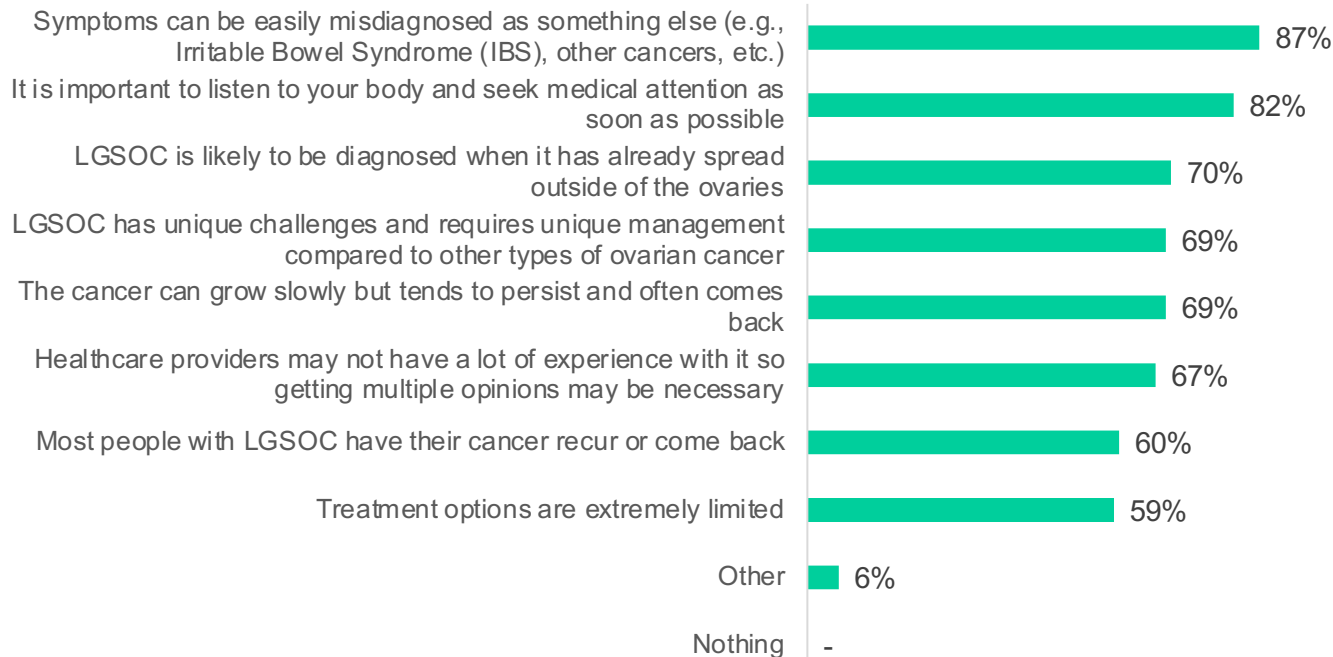
“ The biggest challenges I face with this condition are the uncertainty and the depression that it can bring initially, because you feel out of control...I know it's not going to be pretty because of course you look into all the things that are likely to happen and they're not nice. They're not things you would ever choose. So you are always on your guard. You are aware of every ache and pain being potentially a bowel blockage or a tumor or something growing again. – Alex, U.K.

“ The emotion that I feel from the physical impacts that this condition has had on me is devastation. I never thought I would be so tired and slow. And when my friends, we went to Oregon for a wedding this last weekend. When I go to this wedding, they have to go on a hike without me. I stayed home and slept. I never thought that would be me. I was always the one coming up with things to do and encouraging people to get out, and now it's me saying, "Well, if I feel okay, I'll join you, but most likely I'm going to have to take it easy." And to have that as my future and potentially as long as I'm on this maintenance medication is horrible. – Connie, U.S.

The two biggest things LGSOC patients want women to know are that symptoms are easily misdiagnosed and that it's important to listen to your body

2 in 3 want women to know HCPs may not have a lot of experience so multiple opinions may be necessary

Most Important Things For Women To Know About LGSOC



Qualitative Findings



Advice

- The biggest pieces of advice women have to offer echo the quantitative findings – listen to your body, seek several opinions, don't take no for an answer because symptoms are common and often misdiagnosed.
- A few mention that the field as a whole is underfunded and needs greater attention from scientists, researchers, pharmaceutical companies, and prospective health care providers.
- A couple would like healthcare providers to take recurrent symptoms more seriously and to treat the whole patient, not just the condition.



My advice would be to check in with your gynecologist. Pay attention to your body, because you know your body better than anybody else, a doctor, anyone. If anything feels strange or off, get it looked at. Don't stop until you find somebody that can help you or that will listen to you. – Deana, U.S.

Women and anybody that was born with ovaries, definitely need to know that you can get ovarian cancer at any time in your life, even if your ovaries have already been removed. And you need to know the symptoms and you need to be your own advocate. And don't take no for an answer. If you know that something is up in your body that is not normal, continue to push and ask for a transvaginal ultrasound and a CA 125 blood test. – Ellie, U.S.



Low grade serous ovarian cancer is so rare that it's just completely understudied. The general ovarian cancer fundraising does not go towards research on low grade. There's really been no development in treatment in many, many years. So I think that as a whole, medical oncologists and researchers have a lot more work to do, but I think that it's a really small field. I think that there's only a handful of people who have dedicated their career to working on low grade, and I am forever grateful that they have chosen to do that. But I think we need to get the word out there so that new people coming into the field take an interest in researching low grade. And there's just so much more to learn about what causes it, what treatments could be effective, and how to support people who live with it. – Ellie, U.S.

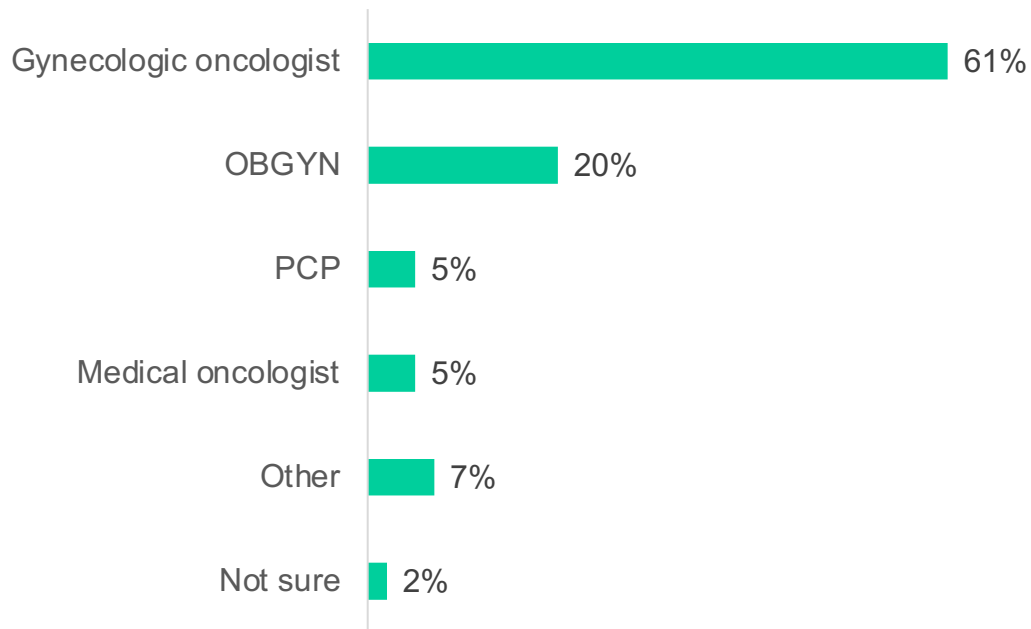
Address not only the disease, because we are not a case. We are not a cancer. We are a person. We are a whole individual. It's not just our reproductive organs that are affected. Our minds are affected, our relationships are affected, so helping connect us with those resources who can help treat the whole person I think is so important. – Connie, U.S.



Appendix

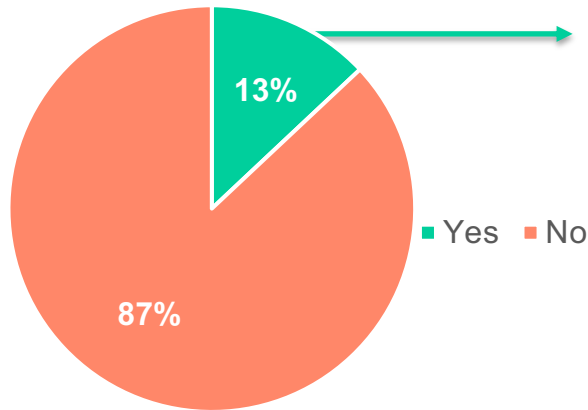
Most women were diagnosed with LGSOC by a gynecologic oncologist

Type of Healthcare Provider Who Diagnosed LGSOC



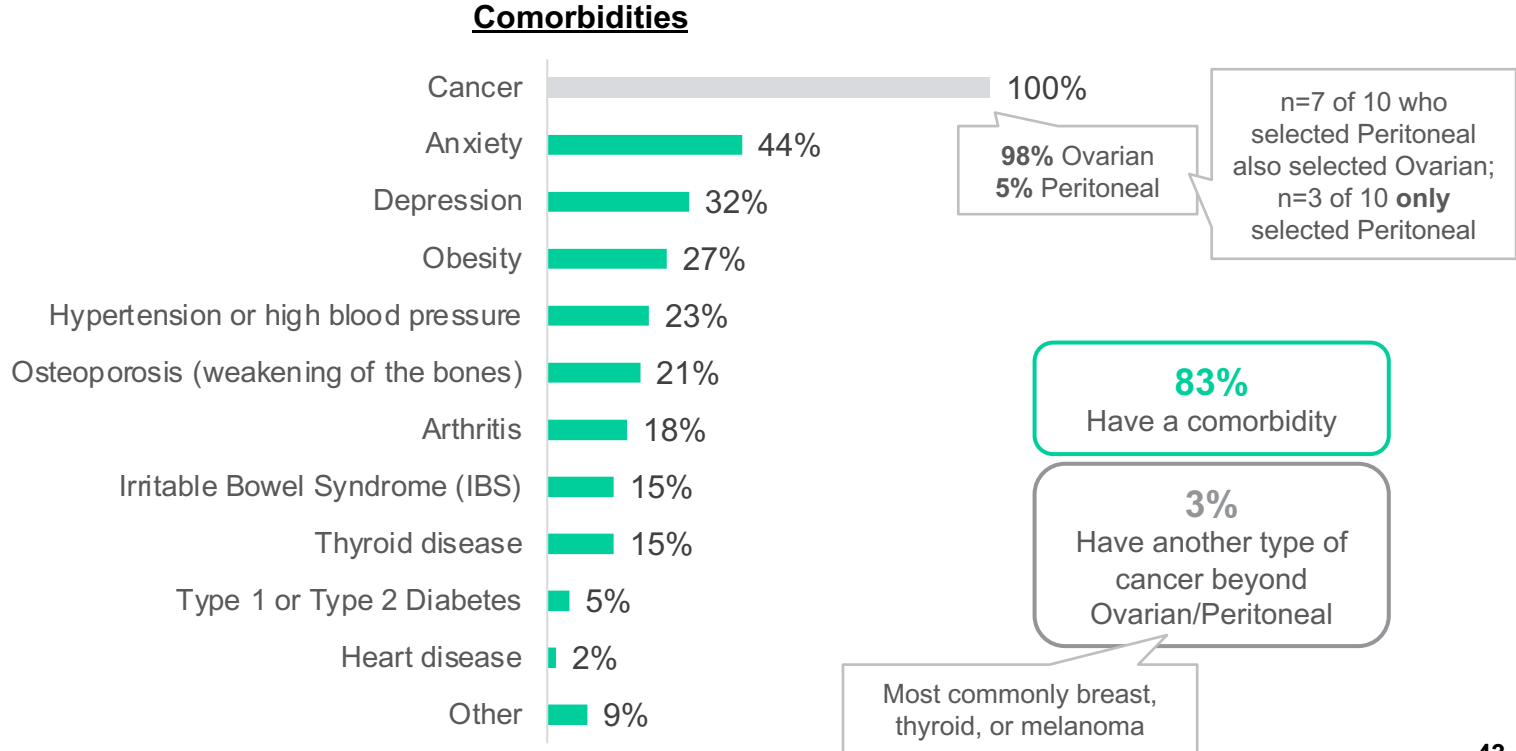
Only ~1 in 10 women report participating in an LGSOC clinical trial, most of whom were quite satisfied with their experience

Clinical Trial Participation



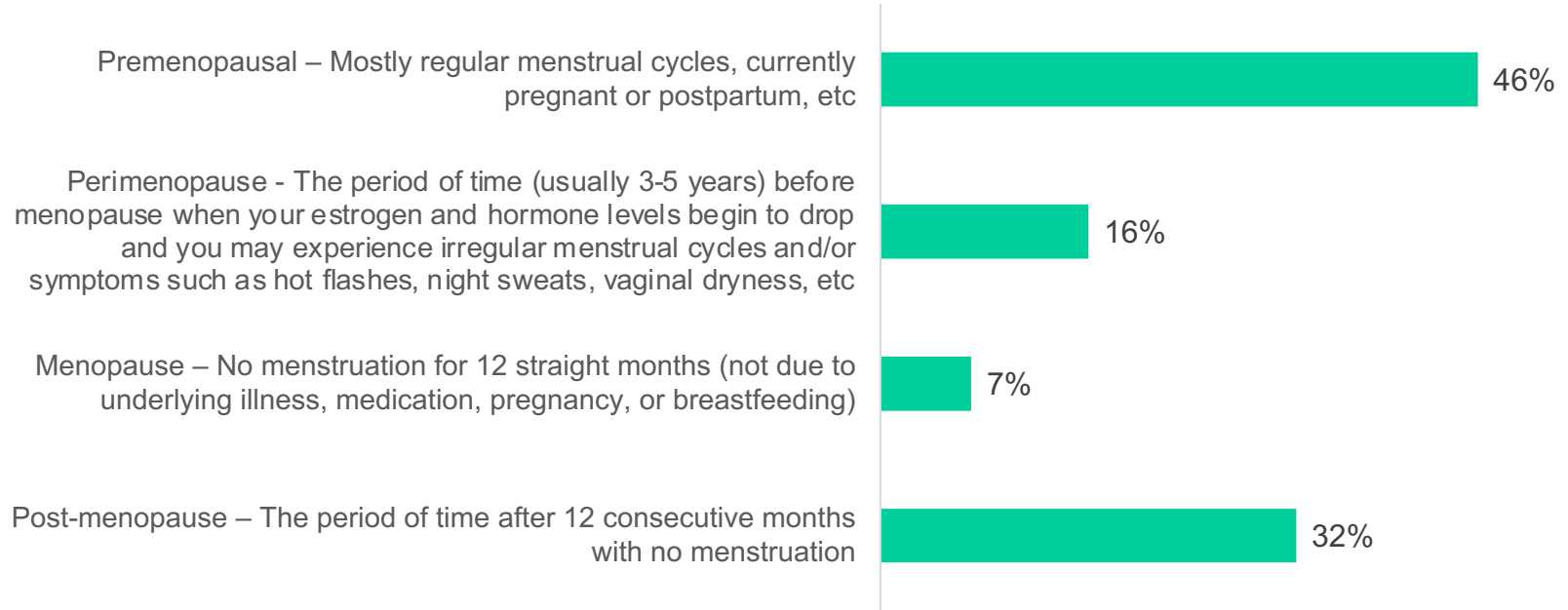
~9 in 10 who participated in a clinical trial are somewhat/very satisfied with their experience, including ~6 in 10 who were very satisfied**

The most common comorbidities with LGSOC are anxiety and depression; 1 in 5 experience osteoporosis



Women are split on what reproductive stage they were at the time of their LGSOC diagnosis, with ~half being diagnosed when they were premenopausal

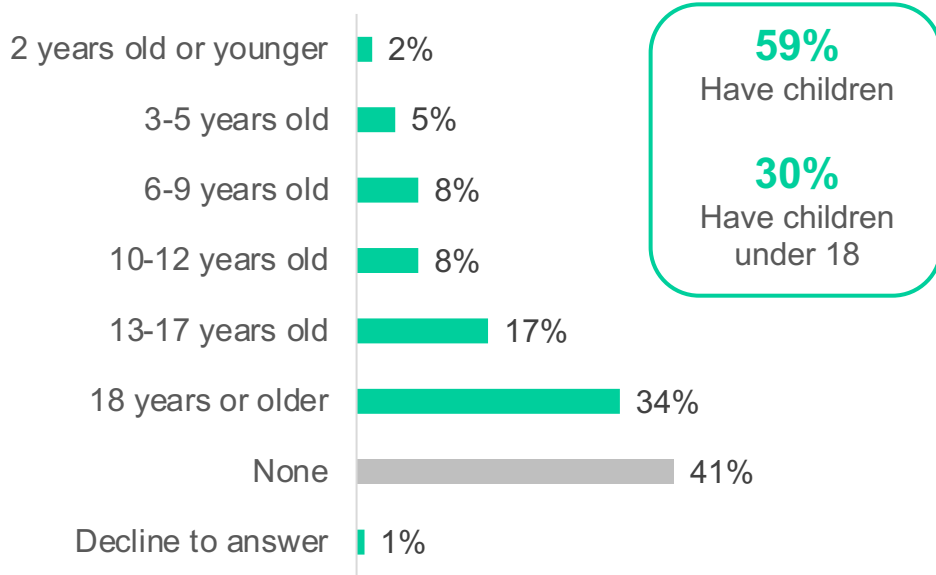
Reproductive Stage at Time of LGSOC Diagnosis



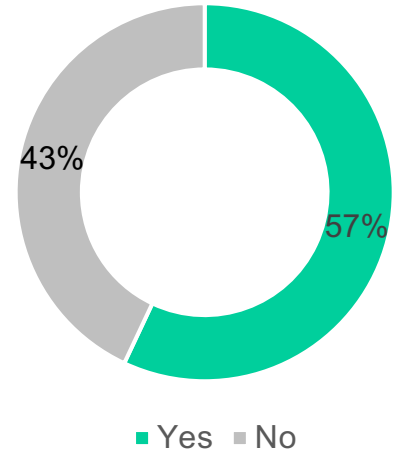
Around 6 in 10 women with LGSOC have given birth or have children, with 3 in 10 being the parent of a child under 18

Parental Status

Have children



Ever Given Birth



Demographics

Demographics

Base: All Qualified Respondents [n=186]	
Country	
United States of America	57%
United Kingdom	18%
Canada	8%
New Zealand	4%
Australia	4%
Italy	1%
France	1%
Spain	1%
Germany	1%
Other country	6%
Age	
18-24	1%
25-34	13%
35-44	23%
45-54	33%
55-64	14%
65+	16%
<i>Mean</i>	48.9
Marital Status	
Never married	13%
Married/living with partner	72%
Divorced	11%
Separated	3%
Widowed	2%

Base: All Qualified Respondents [n=186]	
Employment	
Employed (NET)	62%
Employed full time	43%
Employed part time	19%
Not Employed (NET)	38%
Retired	16%
Not employed, unable to work due to disability or illness	14%
Not employed, not looking for work	4%
Stay-at-home spouse/partner	2%
Not employed, looking for work	1%
Student	1%
Urbanicity	
Urban	25%
Suburban	45%
Rural	30%