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# Understanding the needs and perspectives of ovarian cancer patients when considering PARP inhibitor maintenance therapy: Findings from two online community events

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ABSTRACT

*Objective:* The online environment is an ideal setting to understand how many women seek, receive, and understand information about cancer treatment. The purpose of this study was to understand women's needs and information-seeking around Poly ADP ribose polymerase (PARP) inhibitors, an oral medication commonly prescribed as maintenance therapy at the conclusion of primary chemotherapy for ovarian cancer.
*Methods:* We held online discussion events with two social media communities, #gyncsm social media on Twitter and the Smart Patients ovarian cancer community, in November 2020, to sample ovarian cancer patient perceptions of, and information seeking about PARP inhibitors. Focused questions were presented to both communities, with participants able to answer and elaborate upon these questions, as well as to add their own comments or topics. Qualitative content analysis was performed on the transcripts from the two online events.
*Results:* A total of 254 unique tweets and 71 messages were generated from the Twitter and Smart Patients conversations, respectively. The majority of the content from these two events could be categorized into five major themes: (1) concerns about side effects, (2) expectations of benefit, (3) desire for more information regarding clinical trials, ) (4) desire to better understand the relationship between mutation status and PARP inhibitor effectiveness, and (5) financial toxicity. Misinformation was rarely identified.
*Conclusions:* Women with ovarian cancer who are engaged in online patient communities have numerous educational needs regarding PARP inhibitors. Given the complexity of clinical research on PARP inhibitors, patients would likely benefit from patient-centered educational tools.

## 1. Introduction

Social media and online health communities are increasingly becoming a part of the way in which cancer patients find, discuss, and share health information and resources (van Eenbergen et al., 2018; Tapi Nzali et al., 2017). Studies have shown that cancer patients' anxiety may decrease when their perceived knowledge increases through participation in social media support groups (Katz et al., 2016; Attai et al., 2015). The use of these online resources by patients may benefit them by increasing engagement and empowerment (Sawesi et al., 2016; Liddy et al., 2017), making it easier to find information on treatment and clinical trials (Gentile et al., 2018), and increasing trust in providers who

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also engage in social media (Smailhodzic et al., 2016). However, social media and online communities also have potential to be disadvantageous for patients. Online sites may inadvertently disseminate incorrect or unbalanced information (Loeb et al., 2019; Chen et al., 2018; Allen et al., 2020), allow for exploitation by drug and supplement companies, lead to false hopes or unnecessary expense (Gentile et al., 2018; Solomon et al., 2016), and contribute to feelings of information overload (Gentile et al., 2018; Jensen et al., 2014).

Studies of ovarian cancer patients' experiences on social media have shown that women are often willing to share personal experiences about things such as symptom burden, and may be searching for fulfillment of informational, social, and emotional needs (Lee et al., 2021, 2020; Thomas et al., 2018). Using a Twitter chat forum, Thomas et al (2015) identified a demonstrated need for informational, psychological, and social support in ovarian cancer patients who were transitioning from treatment into survivorship care. Little is known, however, about how women with ovarian cancer use social media and online health communities to guide their active treatment decisions.

One of the newest advancements in ovarian cancer treatment in the past decade is the advent of Poly ADP ribose polymerase (PARP) inhibitors, an oral therapeutic that blocks cancer cells' ability to repair their own DNA (Moore et al., 2020). For women with advanced-stage ovarian cancer who harbor a BRCA mutation or similar genetic defect, PARP inhibitor maintenance therapy can extend progression-free survival (PFS) by about a year when given after completion of primary chemotherapy (Coleman et al., 2019; González-Martín et al., 2019; Ray-Coquard et al., 2019). However, approximately half of ovarian cancer patients do not carry germline or somatic mutations or similar genetic changes that confer a PARP inhibitor benefit (The Cancer Genome Atlas Research Network, 2011). These woman are expected to gain only 0-3 months PFS from PARP inhibitor maintenance therapy (Coleman et al., 2019; González-Martín et al., 2019; Ray-Coquard et al., 2019). Moreover, maintenance PARP inhibitor therapy was approved prior to the publication of sufficient data to support its overall survival benefit, quality of life benefit, and cost effectiveness for patients (Berchuck et al., 2017). Despite the convenience of oral administration, PARP inhibitors carry adverse effects of low blood cell counts, nausea, fatigue, a 1% risk of myelodysplastic syndrome or acute myeloid leukemia (Morice et al., 2021), and financial toxicity, with out-of-pocket co-pays averaging $305 per month, and sometimes exceeding $1,000 monthly (O'Cearbhaill, 2018; LaFargue et al., 2019; Harrison et al., 2021).

Following a succession of highly successful and publicized randomized trials (Coleman et al., 2019; González-Martín et al., 2019; Ray-Coquard et al., 2019), patients with ovarian cancer are very eager to learn about and try these medications. Given that the decision to take a PARP inhibitor is likely based on a wide variety of factors, patients may turn to online communities as a means to get information or discuss their decisions with fellow patients. To better understand how women learn about PARP inhibitors and how they utilize social media to discuss the decision-making process, we conducted a qualitative analysis of Twitter and Smart Patients focus group events on the topic of PARP inhibitor maintenance therapy.

## 2. Methods

This study was determined by the authors' institutional review board to be exempt from review (Pro00107704). The study was conducted through retrospective content analysis of a scheduled Twitter event and a discussion conducted on an online social network, Smart Patients.

On November 11, 2020, we held a one-hour Twitter event on the topic of PARP inhibitors, moderated by a social media expert (CL), a survivor and patient advocate (DS), a gynecologic oncologist (LJH), a psychologist with expertise in qualitative research (LF) and a patient preferences research expert (SDR). Twitter is a social media platform on which members share thoughts and information with one another in the form of discrete "tweets" of up to 280 characters each. Our one-hour Twitter event was promoted by #gyncsm (gynecologic cancer social media), a community created in 2013 to bring together individuals whose lives are affected by gynecologic cancers. The event was advertised to ovarian cancer patients and survivors, individual health care providers, cancer centers, the Society of Gynecologic Oncology, the Foundation for Women's Cancer, national and state ovarian cancer awareness organizations, and co-promoted by the Smart Patients online health community. To engage patients in targeted conversations, the Twitter chat posed 6 question prompts that were developed by the moderators (Table 1). Participants responded to questions by tagging their tweets to the specific question (T1A, T1B, T2, T3, etc.). A transcript from the event was collected and provided by Symplur, a company specializing in health care social media analytics.

Beginning on the morning following the Twitter event, we held an 'Ask the Expert' asynchronous conversation on the topic of PARP inhibitors on Smart Patients (www.smartpatients.com), an online social network established in 2012 to bring together patients and caregivers with a variety of illnesses and cancers for peer-to-peer online community support. The conversation, conducted within the ovarian cancer community, was moderated by a Smart Patients staff member and two gynecologic oncologists (BAD and LJH), and remained open for 4 days following the Twitter event. The majority of Smart Patients members interact with the site on a weekly basis, and 30% of users interact daily (Hoskote et al., 2021). Data scientists at Smart Patients provided the study team with a full de-identified transcript of the thread of messages from the 4-day conversation for content analysis.

For the content analysis, a coding schema was developed to analyze the tweets and Smart Patients messages. The authors read through the full transcripts from both events to develop an initial coding framework around which to organize the data. After meeting to discuss, the final codebook was created. The initial codes and definitions were applied to both transcripts by two independent coders. A team consisting of the two coders and two of the Twitter/Smart Patients gynecologic oncologist moderators then met to discuss and reconcile differences in application of codes. Through discussion, the authors identified major themes in the coded data, created new codes and restructured current codes as new themes were discovered or reinterpreted. Regular debriefing and descriptive memos were used to enhance rigor and trustworthiness of study findings (Gale et al., 2013). Next, a coder summarized the data by the major themes with feedback from the larger research team. After initial coding was completed independently by both coders, they came to a consensus on all applied codes. Descriptive analysis was then performed on the type and frequency of the various themes from the two transcripts.

## 3. Results

### 3.1. Twitter chat

The Twitter chat had 29 participants, who together produced 254 tweets; each participant posted an average of 9 tweets. In an intra-chat

**Table 1**
Twitter Chat Questions

| Order | Question |
|---|---|
| T1 | A. How have you gotten information about PARP inhibitors? Have you seen advertisements (print, TV, social media)?<br>B. How do social media sources (including online patient communities) play a role in your information gathering about possible treatments? |
| T2 | Are PARP inhibitors a better fit for certain women than others? |
| T3 | What are pros and cons of maintenance therapy with PARP inhibitors? |
| T4 | Is there anything you wish you had known earlier about PARP inhibitors? |
| T5 | How do out of pocket expenses play a role in decisions you make about taking a PARP inhibitor? |
| T6 | Are you aware of the current ASCO guidelines about PARP inhibitor maintenance therapy? |

poll, 13 participants identified themselves as: patient/survivor-8, provider-2, advocate -2, or caregiver-1. Of 9 participants responding regarding PARP inhibitor use, 5 had never taken a PARP inhibitor, 3 were currently taking one, and 1 had taken a PARP inhibitor in the past. The contributors with the most posts in the Twitter conversation included the gynecologic cancer social media group (@gyncsm), individual participants, and one of the gynecologic oncologist moderators. Roughly 30% of tweets were re-tweets of previously stated comments within this conversation.

### 3.2. Smart patients discussion forum

The Smart Patients discussion forum began on November 12, 2020, at 8 am Eastern Standard Time and remained open until November 16, 2020, at 8 am Eastern Standard Time. The discussion forum was viewed by 600 members. 28 members contributed to the discussion, producing 71 unique messages. The word cloud in Figure 1 shows the most commonly used words during the Smart Patients event; these include "PARPi", "cancer", "treatment", and "side effects". Additional commonly used words surrounded the information seeking that women are engaging in, including "read", "understand", "deciding", "question", "prepared", and "informed".

### 3.3. Content analysis of social media comments

Themes that emerged during the Twitter and Smart Patients events were largely driven by the questions posed by moderators, but these questions stimulated elaboration by patient participants. The five major themes were the burden of side effects, the motivating aspects of PARP inhibitors and expectations of benefits, desire for information surrounding clinical trial results, desire to better understand the relationship between tumor mutations and the effectiveness of PARP inhibitors, and financial toxicity. Table 2 shows the percentage of patient messages in the Smart Patient forum that discussed each of these themes.

Patients largely had differing feelings regarding side effects and whether they outweigh potential benefits. This topic emerged in both the Twitter and Smart Patients transcripts. Some patients were willing to experience a few side effects to gain survival benefits. There were patients who had already taken PARP inhibitors who had found ways to manage side effects such as constipation and insomnia or did not seem to experience side effects to the same degree as others. Although the moderators discussed the benefits in terms of progression-free survival, it is unclear whether patients understood this term; patients referred to the benefits of being able to "live a lot longer" and have "more time in remission".

> *"I've been very lucky in that the only side effect that I've had is constipation (which I finally seem to be able to manage consistently)."*
> *"Merely desire to live a lot longer, of course with tolerable side effects."*
> *"I figure that I can stop maintenance treatment if the side effects are too much. I'd rather see if I can get more time in remission."*

Other patients were more hesitant about starting PARP inhibitors because of the concerns about side effects. These worries often originated from anecdotal information from physicians and other patients on social media who had experienced severe side effects such as kidney problems, thrombocytopenia, and gastric discomfort. One patient communicated concerns that the side effects would feel similar to the unpleasant symptoms experienced while on platinum-based chemotherapy. Some patients expressed expectations of only gaining a few months of extra time, and thus felt that any side effects would not be

**Table 2**
Percentage of patient messages discussing each of the five major themes in the Smart Patients forum.

| Theme | % Of patient messages discussing theme |
|---|---|
| Side effects | 24% |
| Desire for more information from clinical trials | 22.5% |
| Desire to better understand the relationship between genetic mutations and PARP inhibitors | 22.5% |
| Expectations of benefit | 20% |
| Financial toxicity | 8.5% |

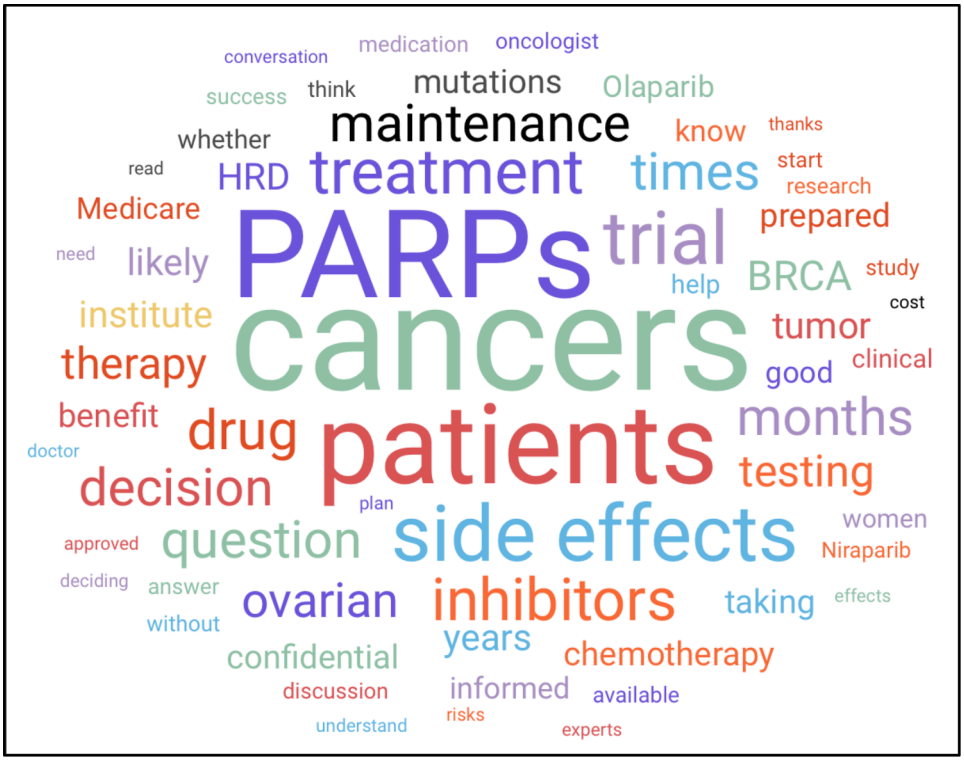


**Figure 1.** Cloud showing word frequency from Smart Patients discussion forum on PARP inhibitors. Larger fonts demonstrate more frequently used words.

worth that.

"*I was very concerned about some of the low-probability but high-risk side effects"*
*"I have read the horror stories from many on this site about some of the side effects they are experiencing from maintenance therapies and making them question if the cons are worth it."*
"*Two women I know – one stopped taking it because of side effects and the other decided against starting it because of the side effects.*"

Patients did not draw consistent conclusions about the benefits of PARP inhibitors. The majority of patients indicated that they read and researched on their own to develop their opinions, but they had many questions regarding tangible benefits that they might experience. The potential benefits of taking a PARP inhibitor were expressed in different ways, including an increase in lifespan, progression-free time, preventing versus delaying recurrences, and avoiding another chemotherapy regimen.

*"It would sure be great to have a year or close to it in remission!"*
*"[I] wanted to try to do everything I could to prevent or delay a recurrence."*
*"I'm willing to take the risk with a PARPi after recurring 6 months after frontline…I'd rather see if I can get more time in remission…"*

Several patients were uncertain about whether outcomes are worth it.

*"I have also read conflicting opinions from medical researchers/scientists on whether if indeed the benefits outweigh the risks"*
*"I think gaining 2-3 extra months without much quality of life would not be worth it to me."*
*"I keep reading about others having concerns about risks outweighing the benefits"*
*"Whether women who take a PARP inhibitor are more likely to be cured or live longer is still not known…"*

An overwhelming theme that emerged from the transcripts was a desire and need for patient-centered educational materials about the information presented in clinical trials. Many patients had attempted to interpret results from past and ongoing clinical trials as a way to answer their specific questions about PARPs, including whether PARP inhibitors cross the blood-brain barrier, and their role in low volume recurrences or specific tumor types. Patients also conveyed feeling overwhelmed with the data, particularly conflicting information reported from different sources. Patients in the Smart Patients group did not reveal whether they were reading clinical trial information from the primary sources, or from interpretations on drug company websites or other resources. In the Twitter forum, patients did disclose where they were obtaining their information: directly from clinical trial reports, pharmaceutical websites, Twitter, and Facebook.

*"I spent a couple weeks gathering information…I find researching clinical studies to be my go-to."*
*"I am interested in the study results of how well it keeps the cancer from returning after being on [olaparib] 2 years?"*
*"I often found myself in tears because I felt there was just not enough data to make a good decision."*

During the Twitter chat, patients were also eager for more information; two of the most commonly retweeted messages were from a provider informing participants of the American Society of Clinical Oncology (ASCO) PARP inhibitor guidelines and where to find this information online.

A few examples of misinformation did emerge in the Smart Patients transcript, specifically in descriptions of information presented in clinical trials.

*"It looks like Rubraca has a longer PFS of 11 months even for those of us without BRCA or HRD+ status. That's a bit longer than Zejula (9.3)."* (misinformation)
*"The PARPi studies didn't break out results separately between somatic and genetic BRCA"* (misinformation)

Similar to the need for patient-friendly information on clinical trial results, confusion over mutation status and its role in PARP inhibitor eligibility/effectiveness was a common topic of conversation in the Smart Patients discussion and Twitter chat. Patients were uncertain about how tumor sequencing and BRCA status affects their ability to take PARP inhibitors and their ability to participate in different clinical trials.

*"Are there any PARP inhibitors out there for patients like myself who are negative for BRCA…"*
*"I was not sure that…[olaparib] was going to be as good a fit for me since I didn't have genetic BRCA"*
*"Depending on the outcome of her gene sequencing test, does that possibly give better options for treatment?"*
*"My gyn Onc (and others, according to their patients) don't see much benefit for those not BRCA+ and HRD+ and don't like to prescribe them to those patients."*

Patients were unsure how to obtain information about mutations carried by themselves or their tumor.

*"The delayed start of [olaparib] was because the [doctor] thought tumor testing with initial onset of ovarian cancer wasn't beneficial. I asked twice to have tumors profiled."*
*"I was hoping that testing for HRD would help me determine how much benefit a PARPi might be for me."*
*"I had originally wanted to get an HRD test to help me decide whether to participate in the Athena trial [NCT03522246]."*

In the Twitter event, one of the three most retweeted messages was regarding mutation testing: *"Note - Testing can be done on a person AND on their tumor to look for mutations. We covered this on a previous #gyncsm chat if you want to learn more about how these differ"* (Table 3).

Patients also had practical concerns about PARP inhibitors, including financial toxicity. Cost was highlighted as being a deterrent to taking PARP inhibitors, with multiple patients in both the Twitter chat and on the Smart Patients forum stating that the out-of-pocket monthly costs may make the drug not worth taking at all. Patients were also confused about the different insurance prescription drug plans and whether or not PARP inhibitors are included in coverage.

*"…cost is a big issue for older patients or people on Medicare due to cancer disability…" "They might turn down the drug just on the basis of cost."*
*"My out-of-pocket for this was $6,500 a month and my cancer still came back…I just don't think it is worth it."*
*"Most [ovarian cancer] women I know [in real life] and [social media] would like to try a PARP. But aren't aware that manufacturers have financial assistance to help with the astronomical cost…"*

**Table 3**
The three most retweeted messages during the Twitter event.

| Quotation | Retweets |
|---|---|
| Note - Testing can be done on a person AND on their tumor to look for mutations. | 4 |
| T6 Here is a link to the full ASCO guidelines on PARP inhibitors in ovarian cancer. https://t.co/wfU3gqhkSB 2/2 #gyncsm | 4 |
| ASCO recommends that all women with advanced stage ovarian cancer who have a good response to initial chemotherapy be offered PARP inhibitor maintenance therapy and make a shared decision with her provider | 4 |

## 4. Discussion

Understanding the patient's perspective in medical decision-making is an important aspect of care, especially when considering a treatment that is still at the forefront of evolving ovarian cancer research. The aim of this study was to sample participant communications in two online educational forums to gain insight into ovarian cancer patients' decision making about PARP inhibitor treatment. Our study highlighted factors that women with ovarian cancer consider when discussing PARP inhibitor use, how women obtain information regarding PARP inhibitors, topics surrounding PARP inhibitors that women are struggling to understand, and the potential for circulation of misinformation through social media and online communities. To our knowledge, no prior research has attempted to elucidate how women with ovarian cancer are talking about PARP inhibitors in online communities. The data gathered represents a rich source from which to build educational content for use during shared decision making.

We found that there are large information gaps and substantial patient uncertainty surrounding PARP inhibitors, including who will benefit and by how much. Patients are actively seeking nuanced information about exactly which tumor mutations, cancer types, locations of spread, and previous treatment courses make one more or less likely to benefit from PARP inhibitor maintenance therapy. To obtain this information, patients are doing their own research that encompasses past, present and future clinical trials. Some patients stated that they were sifting through medical research for answers to their questions. Others quoted information that utilized brand names of PARP inhibitors, suggesting that they might be getting their information from secondary sources such as pharmaceutical websites or other online interpretations of clinical trial results. The fact that some patients are doing their own reading and researching shows strong motivation and initiative; however, this also leaves the door wide open for potential misinformation which may then be re-circulated on social media. Even in our small sample of social media communities, several instances of misinformation spreading occurred. The misinformation circulated in the Smart Patients transcript was primarily regarding the interpretation of clinical trial results, which further reinforces the need for more patient-centered forums to disseminate this information. Additionally, this research highlighted significant confusion surrounding tumor mutations and how they affect patients' probability of benefit from PARP inhibitors. Some women expressed confusion or frustration over how to obtain genetic status information about their specific tumor, and one woman was considering enrolling in a PARP inhibitor clinical trial not for access to the medication, but to find out her mutation status.

In a previous discrete choice experiment of the stated preferences of ovarian cancer patients for PARP inhibitor treatment choices, our group demonstrated that patients' choices were largely driven by overall survival benefit and out-of-pocket costs, and that patients would tolerate some side effects in exchange for a 3-4 month gain in progression-free survival (Havrilesky et al., 2020). However, we do not have an understanding of how, outside of a survey with embedded education, patients obtain accurate information about expected side effects, cost, and survival benefits. A prior Twitter chat of similar format and scale held in 2018 by the #gyncsm group similarly highlighted feelings of information void by ovarian cancer patients entering survivorship (Thomas et al., 2018). The authors similarly highlighted the need for more patient-friendly information to guide patients through a portion of their ovarian cancer journey. Thus, the present study adds to the existing evidence indicating that ovarian cancer patients are looking for support in the form of information to guide them through some of the difficult decisions they must make.

The biggest limitation of this study is the very small sample size of women engaged in online forums. A large proportion of gynecologic oncology patients likely do not engage with social media; we don't know how their perceptions differ from the ones described here. However, the purpose of these two online events was merely to sample the perceptions of members of the patient community who are active on social media regarding PARP inhibitors. For these patients, social media appears to be an acceptable way to discuss the complexities of PARP inhibitors. In the Twitter event specifically, several patient participants stated that they were active in groups specific to discussing PARP inhibitors on Facebook and Twitter. Although ours was a small sample of patients, this work clearly demonstrates patient desires for more understandable information surrounding PARP inhibitors. It also demonstrates that some women currently use online communities and social media to learn and discuss information about PARP inhibitors, making this a feasible platform that can be utilized to disseminate accurate educational information.

Social media resources and online communities are reasonable outlets to share information regarding PARP inhibitor treatments with ovarian cancer patients. This is a relatively new way to access patients beyond our own institutional walls. These patients are eager to learn about PARP inhibitors and demonstrate a need for support in their quest for information. Many factors are at play in a woman's decision concerning PARP inhibitor maintenance therapy, and there is a need for patient-centered tools that incorporate both factual information on PARP inhibitors from clinical trials and components of patients' individual preferences.

## CRediT authorship contribution statement

**Karen A. Monuszko:** Formal analysis, Writing – original draft, Visualization. **Laura J. Fish:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – review & editing. **Dorinda Sparacio:** Conceptualization, Methodology, Investigation, Data curation, Writing – review & editing. **Christina Lizaso:** Conceptualization, Methodology, Investigation, Data curation, Writing – review & editing. **Kathryn Burn:** Conceptualization, Methodology, Data curation, Writing – review & editing. **Natalie E. Wickenheisser:** Visualization, Writing – review & editing. **Larissa A. Meyer:** Writing – review & editing. **Shelby D. Reed:** Conceptualization, Writing – review & editing. **Brittany A. Davidson:** Investigation, Writing – review & editing. **Laura J. Havrilesky:** Conceptualization, Investigation, Writing – review & editing, Supervision, Funding acquisition.

## Declaration of Competing Interest

Dr. Fish discloses DCI Core grant funding. Ms. Sparacio discloses presentation of her experience and treatments for ovarian cancer at ArsenalBio. Ms. Lizaso discloses leadership on the Patient Empowerment Network Digital Advisory Board, serving as a Clara Health Patient Advocate, and serving as a National Society of Genetic Counselors Digital Ambassador. Dr. Meyer discloses prior financial support from the NIH, grant funding from Astra Zeneca, consulting fees from GSK, editorial leadership of NCI PDQ Cancer Prevention and Screening board, and stock options in Crisper Therapeutics, Bristol Myer Squibb, Invitae, and Denali. Dr. Davidson discloses payment for presenting at OncLive, payment for participation in GSK, and serving as the Vice-Chair of the Society of Gynecologic Oncology Wellness Committee. Dr. Havrilesky discloses prior grant funding from Tesaro/GSK and Astra Zeneca.

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