



## CADTH REIMBURSEMENT REVIEW

# Patient and Clinician Group Input

durvalumab, olaparib, carboplatin, paclitaxel (Imfinzi and Lynparza)  
(AstraZeneca Canada Inc.)

**Indication:** Durvalumab in combination with carboplatin and paclitaxel is indicated for the first-line treatment of adults with primary advanced or recurrent endometrial cancer who are candidates for systemic therapy, followed by durvalumab in combination with olaparib in endometrial cancer that is mismatch repair proficient (pMMR).

October 28, 2024

This document compiles the input submitted by patient groups and clinician groups for the file under review. The information is used by CADTH in all phases of the review, including the appraisal of evidence and interpretation of the results. The input submitted for each review is also included in the briefing materials that are sent to expert committee members prior to committee meetings. **If your group has submitted input that is not reflected within this document, please contact [Formulary-Support@cda-amc.ca](mailto:Formulary-Support@cda-amc.ca).**

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## Patient Input Template for CADTH Reimbursement Reviews

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Name of Patient Group: Colorectal Cancer Resource & Action Network (**CCRAN**) in collaboration with the Canadian Cancer Survivor Network (**CCSN**) and HPV Global Action.

Author of Submission: Cassandra Macaulay, Deputy Chief Research Officer, CCRAN

### 1. About Your Patient Group

CCRAN is a national, not-for-profit patient advocacy group championing the health and wellbeing of Canadians touched by colorectal cancer and others at risk of developing the disease, by providing support, education and advocacy to help improve patient outcomes by way of longevity and quality of life. CCRAN has expanded its mandate to serve cancer patients outside of the colorectal cancer space through its health technology assessment (HTA) patient evidence submissions, educational events and advocacy initiatives. It collaborates with other tumour type patient advocacy groups to help achieve its expanded mandate because, collectively, it can achieve far more than it could working in silos. ([www.ccran.org](http://www.ccran.org))

### 2. Information Gathering

To help capture the advanced and recurrent endometrial cancer patient perspective for this submission, CCRAN reached out to 12 Canadian trial investigators and/or clinicians via email to request their assistance identifying patients who had/have experience with durvalumab in combination with carboplatin and paclitaxel in the mismatch repair deficient (dMMR)/microsatellite instability-high (MSI-H) disease state, and durvalumab in combination with carboplatin and paclitaxel, followed by olaparib in mismatch repair proficient (pMMR)/microsatellite stable (MSS) molecular subtype patient populations. The email contained a patient recruitment poster (**APPENDIX A**) which clinicians could share with patients or their caregivers who may be willing to participate in a telephone interview to provide their lived experience with not only the therapy under review, but their cancer diagnosis, treatment journey and endometrial cancer journey in general. Each clinician was sent an initial email with subsequent follow up emails, from **September 13<sup>th</sup> 2024** through to the time of writing. Canadian clinicians overwhelmingly identified a lack of patients who had accessed this therapy in Canada, and articulated frustrations that the clinical trial was conducted as a double-blind study making it difficult to accurately identify patients who had accessed the therapy to help inform this review.

An additional outreach plea was also made on **October 1<sup>st</sup> 2024** to 17 U.S.-based clinician investigators who participated in the DUO-E clinical trial via email, as well as to the Society of Gynecologic Oncology and Gynecologic Cancer Initiative. HPV Global Action engaged several Medical Advisors and additional partners in an effort to identify patients who had/have experience with the therapy under review.

The clinician outreach efforts resulted in two telephone interviews with MSS endometrial cancer patients who experienced complete response during the DUO-E clinical trial and were encouraged by their clinicians to provide feedback for this submission, the transcripts of which can be found in **APPENDIX B**.

A social media outreach campaign (**APPENDIX C**) and email blast campaign was shared within CCRAN, CCSN, and HPV Global Action's networks, from **September 15<sup>th</sup> to October 20<sup>th</sup>, 2024**. CCSN produced an endometrial cancer patient experiences survey, which was circulated by both CCSN and CCRAN from **October 9<sup>th</sup> through October 22<sup>nd</sup>**, but unfortunately, no responses were received. Hence, earlier data from a previous endometrial cancer survey which was released on **October 26, 2023**, and closed on **November 8, 2023** (**APPENDIX D**) was utilized to inform this submission in respect of the disease experience and the experience with previously available treatments.

Identifying the patient perspective proved, as anticipated, to be incredibly difficult, hence, CCRAN also undertook an in-depth search of white literature, social media, and patient story blogs in an attempt to identify feedback regarding the disease experience and the therapeutic under review, which resulted in four additional patient perspectives which have been captured in this submission.

These extensive outreach efforts resulted in two telephone interviews with Canadian endometrial cancer patients who accessed the DUO-E trial, four patient experiences shared through blogs or social media, one of whom had experience with the therapy under review (**APPENDIX E**), and the six responses from the CCSN 2023 endometrial cancer patient survey. The sources of data are described in **APPENDIX F**.

### 3. Disease Experience

As the only cancer type exclusively diagnosed in individuals assigned female at birth, gynecological cancers are plagued with inequities including chronic underfunding in research and treatments ([NYSTF, 2022](#); [Nature, 2023](#)). This underinvestment is part of a broader issue affecting women's health in general ([Nature, 2024](#)). Within the umbrella of gynecological cancers, endometrial cancer is the most prevalent, primarily affecting post-menopausal women. The incidence of the disease is rising sharply ([Baker-Rand & Kitson, 2024](#); [CCS, 2024](#)), likely in part due to our aging population and increasing comorbidities. Alarming, despite rapid advancements in the oncology space, endometrial cancer is one of the few cancers wherein mortality rates are actually *increasing* ([ACS, 2024](#); [CCS, 2024](#)); further emphasizing the urgent need for our society, and this committee, to direct efforts and funding to research and treatment options for this pathology. The increasing rates of mortality may disproportionately impact women of colour, as evidence is demonstrating in the United States ([ACS, 2024](#)), though limited race-related health data in Canada complicates assessments in the Canadian context.

Early-stage endometrial cancer is typically treated with surgery, sometimes alongside chemotherapy, hormone therapy or radiation, to improve outcomes. However, in recurrent or metastatic disease, treatment options are limited, and the overall prognosis is quite dismal, as access to new therapeutics for the management of endometrial cancer has been rather stagnant for decades.

Symptoms of endometrial cancer often present as vaginal bleeding in the post-menopausal setting, as experienced by both patients interviewed (**Patient A** and **Patient B**), and can range from spotting to significant bleeding. **Patient F** also recollects *“in sharp detail, waking up hemorrhaging, the ambulance ride to the hospital, the cold delivery of the news that it looked like cancer...”*. In pre-menopausal women, like **Patient C**, symptoms can be subtler – such as *“an abnormal period”* or other abnormal vaginal bleeding. While abnormal vaginal bleeding is the most common symptom in both age groups, and experienced by more than 90% of women with endometrial cancer, individuals may also experience abnormal vaginal discharge, difficulty or pain with urination, pain during sexual intercourse, pelvic pain, or unexplained weight loss ([MSK, nd](#)). **Patient B**, a dedicated runner, noted, in retrospect, that she just wasn't quite her usual, energetic, athletic self: *“I'm a runner, I know I'm 72 now, but just before I was diagnosed, I did a virtual half marathon and I was disappointed in my time, so I did it again and my time was not good again. I blamed it on other things, but looking back I should have known.”*

Patient profiles further reveal the variability in endometrial cancer experiences:

- **Patient A** was diagnosed with stage IVB MSS endometrial cancer at the age of 58, after significant post-menopausal bleeding for a year or more.
- **Patient B** was diagnosed stage I MSS endometrial cancer at the age of 64 and was told following treatment that *“it was only a 5% chance of recurrence, but 4.5 years later it came back.”*
- **Patient C** was diagnosed in 2018 with early-age onset stage III endometrial cancer and shared, *“Apart from an abnormal period, which I tried to address immediately, I didn't have any other symptoms. I'm not your typical age bracket or risk factor group. I'm not overweight, I wasn't post-menopausal.”*

**Patients D, E & F** were identified through an online patient stories blog and detailed disease information is not known, however, their perspectives are being used to inform the endometrial cancer disease experience.

Of note, **Patients A & D** both experienced synchronous secondary primary cancers (thyroid cancer and cervical cancer, respectively).

A diagnosis of cancer is almost universally distressing often triggering intense emotions, such as fear, stress, and anxiety, and an existential crisis. **Patient F** described the terror that continued after she received the devastating news in the hospital, upon *“going home and looking up the frightening statistics that accompany that diagnosis, and praying [her] kids wouldn't do the same.”*

**Patient B** shares how receiving her diagnosis and learning of her subsequent recurrence shook her, and how her thoughts drifted immediately to the family she so dearly loves: *“The first time, I was really upset. My grandson had just been born*

*and I wanted to make sure he got to know me. The second time around, my daughter-in-law this time was pregnant, and again I was like, 'I can't have cancer again, I have to get to know this grandchild.'"*

In the words of **Patient E**, endometrial cancer is an *"awful and sometimes painful"* experience. **Patient B** experienced severe pain during the period of time after her recurrence was detected, but prior to starting treatment, which ultimately required urgent surgery when *"the tumour shifted and there was delay because of covid. It went down into my groin while I was doing yoga, and I was in so much pain I ended up in emergency."*

Upon learning their diagnosis, **Patients A & B** both shared that in the short-term, their immediate concern was how well they would be able to tolerate treatment, and in the long-term the most important aspect was their longevity. In **Patient B's** words: *"The biggest concern was going through chemo and then the other concern was how long I was going to live. I didn't want to hang on for a year if I was going to be sick."* Additionally, feelings of loneliness and isolation are common amongst women who experience endometrial cancer:

*"The most disappointing thing is I have never been able to connect with anyone with endometrial cancer."*

– **Patient B**

*"I knew no one with endometrial cancer, despite the fact that it is the most common gynecologic cancer. I had no idea where to even begin finding such a person. The women who filled the chairs of the chemo suite every third Tuesday were battling right alongside me, but we were all too scared and pumped up on Ativan to be able to really talk to each other."* – **Patient F**

The burden of cancer extends to the family and friends, as well as the social, community, and professional connections of the individual diagnosed with cancer. The weight of this burden disproportionately impacts women, who often experience distress related to the impact that their own diagnosis will have on their role as a caregiver to their children, grandchildren, and spouse, and to their household and employer:

*"Plus, my son is special needs, not severe, but this still added stress..."* – **Patient A**

*"My husband, it was hard on him. We thought he had a heart problem, but the tests came back normal and we think it was just anxiety. I mentioned to my oncologist that I think my husband is having a harder time than me, and he said the husbands often have it bad."* – **Patient B**

*"How do I get through this? How do I take care of myself and my family?"* - **Patient D**, who is the caregiver for her disabled adult son, and needed to navigate not only her own diagnosis, but his care and treatment schedule as well.

One caregiver who completed the endometrial cancer patient survey shared the issues they encountered as a caregiver to an endometrial cancer patient, namely: emotional drain, anxiety/worry, inability to plan ahead, feeling isolated, and feelings of helplessness.

#### 4. Experiences With Currently Available Treatments

**Patient A** underwent a hysterectomy followed by carboplatin and paclitaxel prior to her enrollment in the DUO-E trial. She experienced an allergic reaction to both chemotherapeutics, which was managed with medications. She felt quite fortunate that the only side effect she experienced throughout her chemotherapy was fatigue.

**Patient B** underwent a hysterectomy during her initial diagnosis, followed by incomplete surgical resection after her recurrence, and then carboplatin and paclitaxel in combination with durvalumab, with olaparib added to her treatment regimen following the completion of chemotherapy, as a part of the DUO-E trial. As a result of chemotherapy, **Patient B** experienced hair loss and a drop in her neutrophil count, and the impact of her chemo-induced immune suppression was further exacerbated due to the pandemic: *"It was really difficult because COVID restrictions were still in place. My son-in-law refused to get the vaccine. I was really limited to see my daughter.... We couldn't go out, all the groceries were online. It was a terrible time, and it complicated everything else."*

Endometrial cancer survey respondents accessed a variety of treatment options, including radiation therapy, surgical resection, targeted therapy, hormonal therapy, immunotherapy, chemotherapy, and complementary medicines. These patients experienced various symptoms, including **neuropathy, fatigue, dryness, itching, tightening and/or burning in the vagina, changes in sexual functioning, fluid retention, nausea, constipation, and ‘chemo brain’**, as illustrated in **Figure 1**. Respondents described chemotherapy as *“tough; much nausea and constipation”* noting it *“affects my thinking, loss of stamina, fatigue”*.

The impacts of treatment extend beyond the physical adverse effects related to therapy, as **Patient F** vulnerably shares: *“There are elements of having a gynecologic cancer that can be humiliating – the unending pelvic exams, the shock of being presented with vaginal dilators following radiation, the horror of brachytherapy, and the fear of physical intimacy following treatment. No one prepares you for these things...”*. The significant effects of treatment on sexual health and functioning are all too often dismissed, or inadequately addressed in both clinical care and research ([Agrawal, 2022](#); [Barcellini et al., 2022](#)). Interestingly, but perhaps unsurprisingly, female patients are less likely to be asked about sexual health than male patients, and particularly so if they are beyond child-bearing age ([Agrawal, 2022](#)), as is often the case for endometrial cancer patients. Once again, this highlights one of the many inequities faced by women experiencing endometrial cancer.

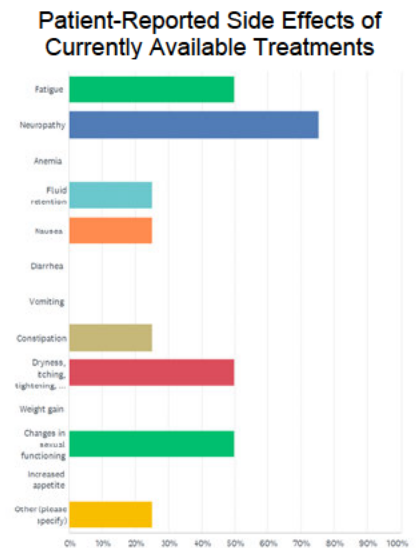


Figure 1

Despite these challenges, these women have approached their treatment with remarkable positivity and strength. **Patient E’s** perspective in particular stands out: *“I wanted to reiterate the mantra that has kept my journey bearable for nearly one year: Armor on. Prayers up. Let’s go! Those words have special significance, as they connect my faith, my feisty personality, and my dogged determination to survive this odyssey.”*

## 5. Improved Outcomes

When asked what improvements they would like to see in cancer treatment (**Q33**), both interviewed patients articulated the importance of improved and timely access to new therapies. Though neither patient was familiar with the term biomarker or biomarker testing (**Q13**), both highlighted the need for an accelerated approval and funding pathway for therapeutics which are currently being accessed by patients with the same genomic markers in another tumour tissue type:

*“I understand the reason why we have drug trials. I get it. If it’s a new drug that’s one thing, but if it’s been used for other cancer types, it would be interesting if there was a different process for the use of drugs that aren’t new but are being investigated for other cancers. Making it faster and easier to get more options, whether it’s funding, or a use of a drug for a different cancer type, getting this process faster. I believe this trial has been going on for years and there must be some safety parts that can be sped up, because it’s been shown to be safe in other cancers.”*  
**– Patient A**

*“Make the drugs more accessible. My family doctor said there was no way I could afford this treatment. Not only that, but I would have to go to the US for treatment. I know one of the drugs has been successful for treating lung cancer and ovarian cancer and has been approved in Canada for these cancers, so why it’s not approved for endometrial cancer is a mystery.”*  
**– Patient B**

Targeted, biomarker-driven precision therapeutics proven to be safe and effective undergo an unnecessarily lengthy process for drug approval and funding for each respective solid tumour type harbouring the biomarker status being targeted. These delays cost Canadian lives. As the field of oncology is shifting towards treatments informed by genomic markers rather than histology, patients want Canada to keep up. Canadian cancer patients, their families, and experts ([Rawson & Stewart, 2024](#)) are pleading for an accelerated review and funding process to improve patient outcomes.

Additionally, when survey respondents were asked which issues they would hope a new treatment would address, 60% of endometrial cancer patients ranked *“prolong life”* as the most important issue. The therapeutic protocol under review has demonstrated significant progression free survival outcomes ([Westin et al. 2023](#)), and clearly offers the ability to prolong life for many, as is so very much desired by patients.

## 6. Experience With Drug Under Review

**Q20 – Q32** of **APPENDIX B** capture the responses of **Patients A & B** who participated in telephone interviews to share their presumptive experience with the drug under review through the DUO-E trial and **APPENDIX E** captures relevant social media posts describing **Patient C's** experience with durvalumab through a clinical trial in Australia. Remarkably, **all patients experienced a complete response.**

**Patient A** accessed the therapeutic protocol (durvalumab in combination with olaparib) from March 2022 – April 2024.

**Patient B** accessed the therapeutic protocol (durvalumab in combination with olaparib) beginning in December 2021 and remained on treatment through to the time of the interview.

**Patient C** began treatment (durvalumab) in 2019 and celebrated her *“two-year remission anniversary”* in February 2024 and was still on treatment at that time.

**Patients A & B** both participated in the double-blinded DUO-E clinical trial and reached out to the author after being encouraged by their clinicians to provide feedback in response to the patient recruitment posters (**APPENDIX A**). The patients each identified the clinical trial through their physicians and were keen to participate. Both shared reliable indicators, suggesting that they did not receive the placebo, and achieved **long-standing and complete response** in the face of a deadly cancer for which a complete response from standard of care chemotherapy would be unexpected. The author acknowledges that an assumption, though reasonably founded, has been made in the collection of this data for **Patients A & B**. In addition to achieving a complete and long-standing response, both patients expressed that though the trial was blinded, they had received indications that they were not in the placebo arm. For example, **Patient A** shared that *“during the trial different parts of my bloodwork were reactive and the probable explanation was that I was not getting the placebo. There were signs.”*

Targeted, precision therapeutics have revolutionized cancer care and are highly efficacious while maintaining a lower side effect profile when compared to their cytotoxic chemotherapeutic counterparts. **Patient A** shared that during her treatment she gratefully experienced minimal side effects related to fatigue: *“Tired, exhausted. That’s it. Very lucky.”* While **Patient B** experienced *“muscle aches, weakness and fatigue”* but when she started an exercise oncology program it relieved the muscle aches, which had been her primary complaint.

Such minimal adverse effects of treatment significantly improve quality of life for endometrial cancer patients, permitting them to engage in meaningful activities in their lives. When asked to rate their quality of life while undergoing treatment, both patients rated their **quality of life as 8 out of 10**, with **Patient A** noting, *“...and that’s only because of the tired, otherwise it would have been a 10.”* The therapeutic protocol was well tolerated by both interviewed patients, who only had to hold treatment upon diagnosis of a second primary or during an infection with COVID-19 (**Patient A & B**, respectively).

**Patients A & C** were able to resume work while undergoing treatment, which is no small feat for a cancer patient undergoing systemic therapy. Not only did this allow them to contribute to society, but it brought meaning and economic stability to their lives. **Patient C** has been able to engage in a fulfilling, active, young lifestyle during her durvalumab treatment: *“I haven’t stopped working (apart from 7 weeks of post surgery recovery) and doing fun things and lucky I haven’t had too horrible side effects as other patients (and my heart and love goes to those that haven’t had it ‘easy’), I have wonderful friends and family and I’m fighting fit.”* She posted online to celebrate her 40<sup>th</sup> birthday, a milestone that she shared her oncologist would not have expected her to achieve had she accessed chemotherapy: *“This is 40. I bloody made it! ...I’m grateful for the people in my life. I’m also grateful for my medical team at Peter Mac for getting me into REMISSION after a four-year shit show. I’m in a job I love and I’m surrounded by the most inspiring and wonderful souls that enable me to keep going.”*

**Patient B** was incredibly grateful to be able to re-engage meaningfully in her family and home life, sharing this had a positive impact on her mental health and wellness: *“Once I was off chemotherapy my neutrophil level came back up, so I didn’t have to worry as much about being around people. I could be around family and even go shopping. I think just being around people improved my mood.”*

Remarkably, **Patient B** was able to resume an active and adventurous travel lifestyle in her 70s while undergoing treatment with the therapeutic protocol for her locally advanced endometrial cancer, limited only by her treatment schedule:

*“During treatment we have travelled to Bhutan and Thailand, and then a few months later we were in South America and then we went to Mongolia. I went riding a horse in Mongolia and it threw me off. I was grateful to have not broken a hip. [laughs]... The hardest thing about the program is I can only be away 26 days, and we like to travel for 6 – 8*

*weeks at a time, so we're spending more in airfare. Originally, I thought I would go off the program because of this restriction, but now there is no way!"*

When a patient feels well, and is tolerating treatment well, it improves quality of life not only for the patient, but for their caregiver and family as well – relieving the mental burden of their loved ones' disease and permitting them the wonderful privilege of engaging with their loved one with some sense of 'normalcy':

*"I didn't have symptoms or side effects, [so my son] didn't have any reason to think about [my journey] very often. I wasn't throwing up all the time or something very visible that I was sick, it was easier for him. It wasn't in his face. To the point that he was getting annoyed with me when I was tired, because otherwise it didn't seem like I was sick."*

**- Patient A**

*"My son is just like 'mom's fine', she's back to normal, so when it comes to babysitting my almost 3-year old grandson, we still take him when I'm not on my infusion days." – Patient B*

Durvalumab is administered by intravenous infusion, and the administration and accompanying time in hospital is completed more quickly than traditional chemotherapy. *"During chemo I was there all day and I came home and wouldn't feel well that day or the next day, and the other drugs I had to take with it made me constipated. That doesn't happen anymore. I go there now and it's only an hour and a half. And I don't get constipated any more."* Olaparib's oral dosing is highly desired by patients, saving time and costs associated with travel for both the patient and their caregiver, as well as the time and costs associated with the infusion time. Time is truly the most precious commodity a cancer patient can have, and any time spent feeling well and away from the hospital allows patients to, at least for a short while, disconnect with cancer, have it leave the forefront of their mind, and feel like their own unique self rather than simply 'a patient'. Time is valued by patients, and the therapeutic under review permits patients and their loved ones more time – both in terms of longevity, as well as time outside of their life as a 'patient'.

## 7. Anything Else?

There is a significant and urgent unmet need for additional precision therapeutics in advanced or recurrent endometrial cancer in Canada. This unmet need is particularly dire for the MSS/pMMR endometrial cancer patient population wherein systemic treatment options have not advanced for decades. To further illustrate the unmet clinical need, the author shares a quote from a Canadian gynecological medical oncologist, which was referenced in a recent submission (**Project Number: PC0381-000**):

*"I maintain there is a huge unmet need for the MMRp and MSS endometrial cancer patient population. These patients do not have good, effective treatments once platinum resistance sets in. End of story. And significant loss of quantity and quality of life especially in women in their 50s and 60s who are primary caregivers to their children and parents and are contributing members of society and are still gainfully employed should be a primary concern. Making up about 70% of endometrial cancer patient population is the MMRp/MSS molecular subtypes and discussions should be left to the clinician and patient, with respect to the tolerance, toxicities, and efficacy of [immunotherapeutics] because these issues are discussed during the patient/oncologist consultation."*

The patients referenced throughout this submission expressed immense gratitude to have availed themselves of access to the therapy under review through a clinical trial, as well as a desire for their own experiences to be able to help others and improve access to this **life-changing** therapeutic protocol. In their own words:

*"It's a win-win. The only disadvantage is having to go to the hospital, but the trial people gave me compensation for parking. The positives far outweigh the negatives: No evidence of disease. No significant side effects. And helping myself and other people." - Patient A*

*"I'm very thankful that I am in the program and very pleased with all my results. I wouldn't leave the program but on the other hand, its disappointing that the drugs aren't more accessible to other people." - Patient B*

*"The oncologist said I wouldn't be here today without this trial as there is no cure and the likelihood of spread is high. Forever grateful and I'm going to take every moment [and] savour life." – Patient C*

When asked if durvalumab +/- olaparib should be made available to all patients who qualify for it, interviewed MSS endometrial cancer patients responded with a resounding, emphatic yes:

*“Absolutely. 100%. If it’s appropriate and the oncologist says it could be effective, it’s a no-brainer that it should be another tool for the oncologist to use. The more tools that the oncologists have to do their jobs, the more chances that you are going to get a better outcome. Give them those tools to get the job done. They have tools to manage symptoms, give them more tools for healthier patients and better outcomes.” – Patient A*

*“Yes, definitely. I want to say it works. Me, an unmedical person, looking at the results for 18 months, and looking at how few people are left in the control group. I would say yes, it works, and I am thankful I can get them.” – Patient B*

**A positive funding recommendation for durvalumab +/- olaparib would represent progress, and hope, in a cancer type that is under-supported and has derived little benefit from the advancements stemming from the new era of precision medicine within the Canadian treatment landscape.** The DUO-E clinical trial’s inclusion of histologies which are less common in endometrial cancer is quite welcome, as all patients, regardless of having a women’s cancer, a rare histological presentation, or a difficult to treat biomarker status, desperately want and aptly deserve timely access to the best potential therapeutic options modern medicine can offer. Gynecological cancers, unique to those assigned female at birth, are plagued by inequities in respect of support, funding, and research advancement. Providing access to this drug will help to reduce this disparity, marking a step towards closing the gap in funding and equity for women’s health in Canada.

Furthermore, gynecological cancers, impacting only those assigned female at birth, receive disparate funding and research, while women uniquely face the challenge and societal burden of being primary caregivers. Women facing cancer often times carry the psychological and mental burden of continuing their responsibilities as mothers, grandmothers, and wives, in addition to any paid professional obligations, while also battling a devastating disease. When endometrial cancer patients are able to access therapeutics which are effective and convenient, with minimal side effects, such as durvalumab in combination with olaparib, it is not only the patient who benefits, but the many individuals she cares for, ultimately reducing the burden of cancer at a societal level. The gynecological medical oncologist referenced in the patient input submission for **Project Number: PC0381-000** articulates this so well based on their extensive clinical experience:

*“There are two groups: the older group who are not well so they are trying to balance their own needs and trying to take care of their own spouses who are themselves not well because they have underlying conditions. And a younger patient group who are taking care of their parents and taking care of their own kids, so the stress of both ends is really difficult, the disruption is unbelievable. Women being the primary caretaker is unbelievable when they themselves are diagnosed with a critical illness. It is quite drastic. This is every conversation I have. It is unique taking care of women. I hear: ‘How am I supposed to do this?!’”*

Durvalumab in combination with olaparib is an effective therapy, which is easy to administer and is well-tolerated by patients, providing women with the ability to re-engage in their lives, their communities, their families, and their work, and in some, look forward to a time beyond cancer. The value and the benefits of this therapy are well in alignment with the perspectives, values, and hopes presented by patients as captured in this submission. Thus, **we strongly implore this committee to provide a positive funding recommendation for this therapeutic protocol in Canada.**



**Appendix: Patient Group Conflict of Interest Declaration**

To maintain the objectivity and credibility of the CADTH reimbursement review process, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.

No

2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.

No

3. List any companies or organizations that have provided your group with financial payment over the past 2 years AND who may have direct or indirect interest in the drug under review.

**Table 1: Financial Disclosures**

Check Appropriate Dollar Range With an X. Add additional rows if necessary.

Company	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
AstraZeneca				X

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

**Name:** Filomena Servidio-Italiano  
**Position:** President & CEO  
**Patient Group:** Colorectal Cancer Resource & Action Network (CCRAN)  
**Date:** October 28, 2024

## ARE YOU AN ENDOMETRIAL CANCER PATIENT WHO HAS RECEIVED OR ARE RECEIVING DURVALUMAB?

**IF SO, WE REALLY NEED YOUR HELP!**

**Durvalumab (Imfinzi®)** therapy is currently under funding review in Canada for the treatment of primary advanced or recurrent endometrial cancer. The Colorectal Cancer Resource & Action Network (CCRAN), Canadian Cancer Survivor Network (CCSN) and HPV Global Action are completing a collective patient input submission on durvalumab in combination with carboplatin and paclitaxel for the first-line treatment of adults with primary advanced or recurrent endometrial cancer who are candidates for systemic therapy, followed by:

- durvalumab as monotherapy in endometrial cancer that is mismatch repair deficient (dMMR)
- durvalumab in combination with olaparib in endometrial cancer that is mismatch repair proficient (pMMR)

We are looking for endometrial cancer patients (or their caregivers) with firsthand experience with this therapy, who are willing to share their valuable story via phone. The patient's perspective will help to inform our patient input submission and provide the expert committee with this valuable insight as they prepare to issue their drug funding recommendation for this therapy in Canada.

The patients (or caregivers) who participate in the interview process will have their privacy and confidentiality respected and maintained at all times. Their input will be completely anonymized in the submission. The telephone interview will last approximately 45 minutes and while there is no guarantee, it may help to get this therapy funded for the treatment of primary advanced or recurrent endometrial cancer throughout Canada.

Patients and caregivers may consent to have their contact information (name, phone # and email address) sent to Cassandra Macaulay and, in turn, the patient/caregiver will be contacted with an appointment time and date for participation in the telephone interview.

Alternatively, the patient/caregiver may contact Cassandra directly to advise of their willingness to participate in a telephone interview to help inform the patient input submission to make a meaningful impact:

Cassandra Macaulay, [cassandra.m@ccran.org](mailto:cassandra.m@ccran.org) or Toll Free: 1 833 792 2726 x1001

*Please contact Cassandra ASAP to schedule the phone interview.*

***Thank you for making a difference in the lives of Canadian endometrial cancer patients and their families! We look forward to hearing from you.***

**APPENDIX B: DURVALUMAB +/- OLAPARIB CANCER PATIENT & CAREGIVER INTERVIEW DATA**

INTERVIEW QUESTION	RESPONDENT A [PATIENT]	RESPONDENT B [PATIENT]
<b>PART A: DEMOGRAPHICS/INFORMATION GATHERING</b>		
1. Interview date, time & method	October 15, 2024 at 3:30 pm ET; telephone interview	October 18, 2024 at 10:00 am ET; telephone interview
2. Patient's current age, age at diagnosis, gender identity	61, 58, female	72, first diagnosis – 64, recurrence – 69, female
3. City, province	██████ Ontario	██████ Alberta
4. A. MARITAL STATUS S/M/D/CL  B. CHILDREN	Single  1 boy – 21 years old	Married  3 children; 3 grandchildren
5. Outreach method: (Canadian clinician, US clinician, etc.)	Canadian clinician outreach	Canadian clinician outreach
6. Treatment centre	████████████████████	████████████████████
<b>PART B: DISEASE EXPERIENCE &amp; EXPERIENCES WITH CURRENTLY AVAILABLE TREATMENTS</b>		
7. When were you first diagnosed with cancer? And with what type of cancer? At which stage was your disease diagnosed?	August or September 2021; Endometrial Cancer; Stage IVB after surgery and everything	2018 – endometrial cancer stage I
8. Were you symptomatic which led to investigations? Tell me a bit about your journey?	A lot of bleeding, for at least a year or more.	I was spotting.
9. How was your cancer detected/ diagnosed?	A series of CTs and a scope, they tried a biopsy but it didn't work.  It started with my family doctor.	The first time I went to our family doctor and she referred me to a gynecologist. They took a specimen and they called another doctor in to look at it and they were pretty confident it was cancer. I was referred to an oncologist and had a hysterectomy and everything looked perfect. I was told it was only a 5% chance of recurrence, but 4.5 years later it came back.  It was a bit of a fluke how they caught it the second time, they thought it was a bladder infection. My family doctor was on vacation, but I was

		panicked with blood in the urine. The other doctor got me in for an ultrasound right away and something didn't look quite right, and then I went for CT and later a PET.
10. How did you feel when you were delivered the diagnosis of cancer?	<p>That's a hard thing to say. I'm a pretty practical person. I knew something was wrong. I wasn't happy but that's a hard question. I'm pretty practical. They gyne who did the scope with the sample had described it and said its usually a sign of cancer. So, I was prepared, I was ready, I knew something was wrong. How advanced it was, that was a shock. The people at [REDACTED] were amazing in answering my questions.</p> <p>I don't know how to describe it really. I wasn't happy, but the people made my options and everything clear. Made me feel like there was lots that could be done. They weren't great options, but obviously chemo and such isn't what anyone wants.</p> <p>I had lots of options so that made me feel better.</p>	<p>For the first time, I was really upset. My grandson had just been born and I wanted to make sure he got to know me.</p> <p>The second time around, again my daughter-in-law this time was pregnant and again I was like, 'I can't have cancer again, I have to get to know this grandchild.'</p> <p>After my recurrence was detected, the tumour shifted and there was delay because of covid. It went down into my groin while I was doing yoga and I was in so much pain I ended up in emergency. One doctor, a fellow, said he couldn't operate as it would be too risky and I might lose movement in my leg. But then when my other doctor came back they said maybe. I was in the hospital for 5 days. I got home and then right away they said I could have surgery.</p>
11. Please share with me the date of your metastatic or recurrent disease diagnosis.	After my hysterectomy, September 21 <sup>st</sup> 2021.	No metastatic disease, but my recurrence was diagnosed in July 2021. No one ever told me the stage, but because its recurring they said it was like a stage III. I still don't understand.
12. Location of your metastatic disease, if applicable.	Uterus and pelvic area, it didn't go far but far enough to be considered stage iv.	N/A
13. Did you undergo biomarker testing for your cancer? If so, at what point in your cancer journey, and what biomarkers / mutations were identified, if any? Was/is your tumour identified to be pMMR/MSS or dMMR/MSI-H?	<p>I don't know. I don't know what that is. I have no idea.</p> <p>[Patient later provided her pathology report which confirmed pMMR disease.]</p>	<p>I don't know. Genetic testing? I think I did, but they wouldn't share the results because of the clinical study.</p> <p>[Patient confirmed she was in the Olaparib arm of the study, thus the disease is assumed to be pMMR].</p>
14. Is there an aspect of your <u>disease</u> that, to you, is more important to control than others?	<p>Symptoms went away as soon as I had my hysterectomy. I guess it was prognosis, and in the short- term it was treatment, but in the long-term it was prognosis.</p> <p>I was in my 50s when I got this, not in my 30s, so I didn't have to hope for like a 50-year remission as I would if I was 25 or 30.</p> <p>In the short-term, I wondered, 'how difficult would chemo be?' We all have friends unfortunately that have had cancer, so I was wondering how chemo would be. Some had it easier than others.</p> <p>Right now, I have thyroid cancer too.</p>	The biggest concern was going through chemo and then the other concern was how long I was going to live. I didn't want to hang on for a year if I was going to be sick.
<b>PART C: EXPERIENCES WITH CURRENTLY AVAILABLE TREATMENTS</b>		

15. What therapies did you receive before durvalumab +/- olaparib, if any?	First, hysterectomy and then I had the standard of care chemotherapy for 1 time every 3 weeks for 6 cycles. Once that was finished, then I was told I might be able to be in the clinical trial. [Confirmed chemotherapy was carboplatin and paclitaxel]	Hysterectomy only the first time. With the recurrence, I had surgery and they couldn't get all the tumour so I knew I had to go on chemotherapy. [Confirmed chemotherapy was carboplatin and paclitaxel]
16. Did those treatments control your cancer? Y or N Please explain.	Yes. Everything was dormant. I was allergic to both the chemotherapy drugs, so getting a system in place so I could take it and not have the reactions took a bit of finessing, but yes.	No. The cancer came back after the surgery and the second surgery they couldn't get it all. I knew they wouldn't be able to get it all for the second surgery.
17. Please describe your quality of life on those treatments.	Tired, very tired. That's it.	It was really difficult because covid restrictions were still in place. My son-in-law refused to get the vaccine. I was really limited to see my daughter. My other daughter was pregnant and then they were isolating themselves, so I could see my daughter and granddaughter on that side sometimes. We couldn't go out, all the groceries were online. It was a terrible time, and it complicated everything else.
18. How long did it take before you progressed on each of those previous therapies?	n/a	4.5 years
19. Was there any particular aspect of the disease that was difficult to control while on those previous therapies? If so, please explain.	No symptoms after hysterectomy. Everything was great except for the tiredness	No, I'm a runner, I know I'm 72, but just before I was diagnosed I did a virtual half marathon and I was disappointed in my time, so I did it again and my time was not good again. I blamed it on other things, but looking back I should have known.
<b>PART D: EXPERIENCE WITH THERAPY UNDER REVIEW</b>		
20. How did you become aware of durvalumab +/- olaparib?	My doctor said there was a trial that I might be able to get into, it might help. I said sure, let's do whatever I can to help get better, or to help research.	When I was diagnosed with the recurrence they told me there was a possibility that I could get into the trial. It hadn't been approved yet in [REDACTED] but they said it could be any day. We held off on the chemo for about a month to wait for the trial. Part of it was my family doctor, as soon as she found out who the doctor in [REDACTED] who was heading it up and she said to go for it.
21. How did you access the therapy under review? E.g., clinical trial, private insurance, self pay, special access?	Clinical Trial	Clinical Trial
22. Access: A. When did you receive durvalumab +/- olaparib (date)?	Around March 2022 for durvalumab, shortly after the standard of care chemotherapy. I took it in combination with the Olaparib, injection and pills.  It was blinded, but the markers in my blood seemed different. Just in conversation my blood work indicated it was possible that I was receiving the study drugs.	December 22 2021, and then I went on Olaparib after chemo at the end of May 2022. I had to wait a couple of weeks because of my creatinine level. They were testing it every week and then I finally reached the point where I could take it.  It's a double-blind trial. But with the Olaparib they had to reduce my dose and with the durva I got a phone call one day and they made a mistake and my drug was going to expire, so I had to go back to get it, I don't think those things would happen with the placebo. I was told it would be about 9 months before I would feel more like myself, and I'm just more tired now. Its almost like my body craves the infusion. Mid-cycle I feel fantastic, and then as I'm approaching it I feel like I need it.
B. In what line of therapy?	First line	First line
C. How many cycles did you receive?	At least two years. At least 24 cycles, I think I remember 33 as a number, but I would have to look it up.	I'm starting cycle 39 tomorrow. Still undergoing treatment.

	I finished April 2024. No further treatment for endometrial cancer.	
<b>23. Side effects:</b> <b>A. Have you experienced any side effects while on this therapy? Yes/no</b>	Yes.	Yes.
<b>B. What were those side effects? Please describe them.</b>	Tired, exhausted. That's it. Very lucky.	Muscle aches, weakness and fatigue. I started having hair thinning about 6 months ago [related to the chemo] Mainly it's the muscle aches. I know I've overdone it when my legs get heavy. Then I know it's fatigue and I just know I have to slow it down a bit. And sore joints, but what I started here in [REDACTED] is a program called ACE and it's an exercise program. And now I don't think I have the muscle aches anymore, just tired. I walk 5 km a day.
<b>24. On a scale of 1-10, how would you rate your QoL while on durvalumab +/- olaparib? 1 being very poor and 10 being very good. Please explain.</b>	8 and that's only because of the tired, otherwise it would have been a 10.  I just needed a lot of naps, after work and that. I was able to work during my treatment. I have the good fortune that I don't have young kids or a husband, so I can put a lot of things aside. If the kitchen floor isn't clean for example, it's not a big deal. My priorities changed because of the tiredness.  I was working fully remotely and my boss allowed me to get it done when I needed. I didn't take advantage of it, but it was nice to have the option. I think because I was working, was part of the reason I was tired. Plus, my son is special needs, not severe, but this still added stress.	If you put covid aside, I'd probably say an 8.  Once I was off chemotherapy my neutrophil level came back up, so I didn't have to worry as much about being around people. I could be around family and even go shopping. I think just being around people improved my mood.  I felt really good, you're always worried about life expectancy when you think about cancer. But after treatment, everything is good.  During treatment we have travelled to Bhutan and Thailand, and then a few months later we were in South America and then we went to Mongolia. I went riding a horse in Mongolia and it threw me off. I was grateful to have not broken a hip. [laughs]  Now, we're going on a cruise. I really like adventure travel, but I'm getting older and on a cruise it's easier, so I'll see if I like.  The hardest thing about the program is I can only be away 26 days and we like to travel for 6 – 8 weeks at a time, so we're spending more in airfare. Originally, I thought I would go off the program because of this restriction, but now there is no way!  We have a cottage on a lake and we are still very active.
<b>25. Did you have any cancer symptoms before starting the therapy? If so, what were they?</b>	None.	No. It's like, how can I have cancer, I'm not sick?
<b>26. If you did have cancer symptoms before starting the therapy, did the therapy help resolve those cancer symptoms? If so, which ones?</b>	N/A	N/A
<b>27. How was response confirmed to durvalumab +/- olaparib? Was it clinically (symptoms resolved and you felt better), biochemically (tumour marker went down), or radio-graphically (CT scan results)?</b>	I had a CT scan last week and haven't received the results, but the last one was no evidence of disease. The disease might still be there, but it's not showing right now.  I'm more than happy to talk about it, because if more people can get this, I'm happy to help get it to them.	Before diagnosis there was the CT and PET and I have a CT every 12 weeks.  There has been no evidence of the disease returning.

	During the trial different parts of my bloodwork were reactive and the probable explanation was that I was <u>not</u> getting the placebo. There were signs. I don't know what they are exactly because I'm not a medical person, but there were signs.	
<b>28. Have you ever had to stop durvalumab +/- olaparib? Why or why not?</b>	Yes, when the thyroid cancer was diagnosed. I never had to stop related to side effects.	It was only delayed when I got covid.
<b>29. Has durvalumab +/- olaparib been easier to use than any previous therapies? Why or why not?</b>	I only had IV infusions of chemo so the pill vs the IV has an obvious difference. I can take it at home, so I don't have to time off work, the basics.	Oh yes. During chemo I was there all day and I came home and wouldn't feel well that day or the next day, and the other drugs I had to take with it made me constipated.  That doesn't happen anymore. I go there now and it's only an hour and a half. And I don't get constipated any more.
<b>30. How has your journey impacted your caregiver /family?</b>	Ummm I have a very small family, just me and my son and a few close friends. My son was naturally concerned. I told him the truth. I was working hard to make it so I would be around for a long time. And that meant going to the hospital to get the trial. He was concerned, but not a big impact. Since he wasn't involved and I didn't have symptoms or side effects he didn't have any reason to think about it very often. I wasn't throwing up all the time or something very visible that I was sick, it was easier for him. It wasn't in his face. To the point that he was getting annoyed with me when I was tired, because otherwise it didn't seem like I was sick.	Ummm I think my daughter being a nurse is more aware of what could happen, where my son is just like 'mom's fine', she's back to normal, so when it comes to babysitting my almost 3-year old grandson, we still take him when I'm not on my infusion days. I'm not sure how much impact it's had on my older grandson, he'll be 8 in December, I was playing with him one day and my hair hadn't grown back after chemo and I was wearing a wig and he was playing and pulled off my hat and my hair went with it, it's a funny family story now. So he knows that cancer isn't good, but doesn't know the details. My granddaughter is 17 now and I just included her on all the emails to keep her informed so she didn't think we were hiding anything from her.  I think it was hard on the grandchildren not being able to see me, but now its just back to normal.  My husband, it was hard on him. We thought he had a heart problem, but the tests came back normal and we think it was just anxiety. I mentioned to my oncologist that I think my husband is having a harder time than me, and he said the husbands often have it bad.
<b>31. Was it worth accessing durvalumab +/- olaparib? Why or why not? Please describe the impact it has had on your life.</b>	Oh yes, 100%.  The negative was going back and forth, taking time off work. My employer was very good, but it still upset the schedule.  The good part is there is no evidence of disease. And now I can help others by giving more data to work with.  It's a win-win. The only disadvantage is having to go to the hospital, but the trial people gave my compensation for parking. The positives far outweigh the negatives - No evidence of disease. No significant side effects. And helping myself and other people.	Oh yes. I'm so thankful for the trial. When we started, we love to travel, so I thought we would probably drop out, but the longer I am on it, I'll say you cant get me out of there! [laughs]

<p>32. Did accessing durvalumab +/- olaparib allow you to fulfill or accomplish anything that you would not have otherwise been able to do had you not accessed the therapy? Please explain.</p>	<p>It's hard to say, not knowing for sure if I was on the placebo or not. I'm hoping that with all my clear scans except for the one anomaly, which happened after I was off for 3 months (when diagnosed with thyroid cancer) and I just wanted to get back on the trial. It scared me. It turned out to be nothing, but it had grown from February to April and by the time I got the PET in August this year it had shrunk back down to how it was in February and was too small to biopsy. That was the only time I got stressed out. It appeared to grow in that time that I was not on the drug. So, I thought I should be back on the drug - please, please, please!</p> <p>I think it helped me to stay disease-free.</p>	<p>If I hadn't gone on it the fear of recurrence would always be there.</p>
<p><b>PART E: PATIENT PERSPECTIVES</b></p>		
<p>33. What improvements would you like to see in a drug therapy that are not currently available in other funded therapies?</p>	<p>That's a hard question. I understand the reason why we have drug trials. I get it. If it's a new drug that's one thing, but if it's been used for other cancer types, it would be interesting if there was a different process for the use of drugs that aren't new but are being investigated for another cancers.</p> <p>Making it faster and easier to get more options, whether its funding, or a use of a drug for a different cancer type, getting this process faster. I believe this trial has been going on for years and there must be some safety parts that can be sped up, because it's been shown to be safe in other cancers.</p> <p>I didn't have significant side effects so I'm not sure I can answer that question. I was lucky. Also my situation was lucky – I don't have little kids that needed to be cared for.</p>	<p>To make the drugs more accessible. My family doctor said there was no way I could afford this treatment. Not only that, but I would have to go to the US for treatment.</p> <p>I know one of the drugs has been successful for treating lung cancer and ovarian cancer and has been approved in Canada for these cancers, so why it's not approved for endometrial cancer is a mystery.</p>
<p>34. Do you believe durvalumab +/- olaparib, has those desired improvements? Why or why not?</p>	<p>Again, I feel like I cant answer this, because I don't know for sure if I had it or not.</p> <p>But it worked for me. I had little side effects. So, it should be out there for people to access.</p> <p>Whether I accessed it or I just had good luck and my disease went dormant, I don't know. Either way I feel blessed. If it's durvalumab that's awesome and get it out there.</p> <p>I think that all the oncologists need all the tools that they can get. It's a tool in their toolbox that everybody should have. To have that option, if it's appropriate to use.</p>	<p>I'm very thankful that I am in the program and very pleased with all my results. I wouldn't leave the program but on the other hand, its disappointing that the drugs aren't more accessible to other people.</p> <p>The most disappointing thing is I have never been able to connect with anyone with endometrial cancer.</p>
<p>35. Would you recommend that durvalumab +/- olaparib be made available to all patients who qualify for it?</p>	<p>Absolutely. 100%</p> <p>If it's appropriate and the oncologist says it could be effective, it's a no-brainer that it should be another tool for the oncologist to use.</p>	<p>Yes definitely.</p>



<p><b>36. Do you wish to add anything about why accessing durvalumab +/- olaparib is so important to cancer patients and caregivers?</b></p>	<p>The more tools that the oncologists have to do their jobs, the more chances that you are going to get a better outcome. Give them those tools to get the job done. They have tools to manage symptoms, give them more tools for healthier patients and better outcomes.</p>	<p>I want to say it works. Me, an unmedical person, looking at the results for 18 months, and looking at how few people are left in the control group.</p> <p>I would say yes, it works, and I am thankful I can get them.</p>
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## Durvalumab (Imfinzi®) Patient Input Submission Communications Toolkit

<b>HAVE YOU TAKEN DURVALUMAB (IMFINZI®) FOR ENDOMETRIAL CANCER? WE NEED YOUR INPUT</b>	<b>YOUR INPUT CAN MAKE A DIFFERENCE!</b>	<b>CONNECT WITH US TODAY!</b>
<p>Durvalumab therapy is currently under funding review in Canada for primary advanced or recurrent endometrial cancer.</p> <p>We're seeking input from patients and caregivers who have firsthand experience with this treatment.</p> <p style="font-size: small;"> </p>	<p>If you or someone you know has been treated with <b>Durvalumab for endometrial cancer</b>, we want to hear from you! Your input will help inform our submission and may make this therapy more accessible for patients across Canada. Join us in making a meaningful impact.</p> <p style="font-size: small;"> </p>	<p>Schedule a confidential phone interview with us – your experience can shape the future of <b>Endometrial Cancer</b> treatment in Canada.</p> <p style="text-align: right;">  Cassandra Macaulay  <a href="mailto:cassandra.m@ccran.org">cassandra.m@ccran.org</a>   Toll Free 1 833 792 2726              Ext. 1001         </p>

### Suggested caption for social media posts:

We are looking for endometrial cancer patients or their caregivers to share their experience with duravalumab (Imfinzi®) therapy for a collaborative patient input submission.

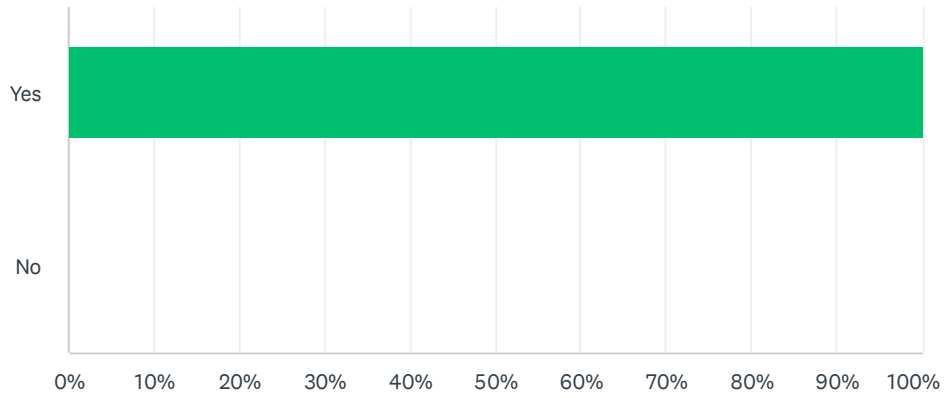
Your input will help inform our submission and may make this therapy more accessible for patients across Canada. Connect with CCRAN [tag: @ccranorg] today to share your story via a telephone interview: [cassandra.m@ccran.org](mailto:cassandra.m@ccran.org) or 1 833-792-2726 ext. 1001.

Your input will be kept anonymous. Let's make a difference together!

#CCRAN #EndometrialCancer #CancerTreatment #ShareYourStory #Imfinzi #Durvalumab  
 #PatientSupport #HealthcareCanada #CancerCare #PatientAdvocacy #CancerResearch  
 #PatientVoices #Hope #MedicalAdvocacy

## Q1 Are you a resident of Canada?

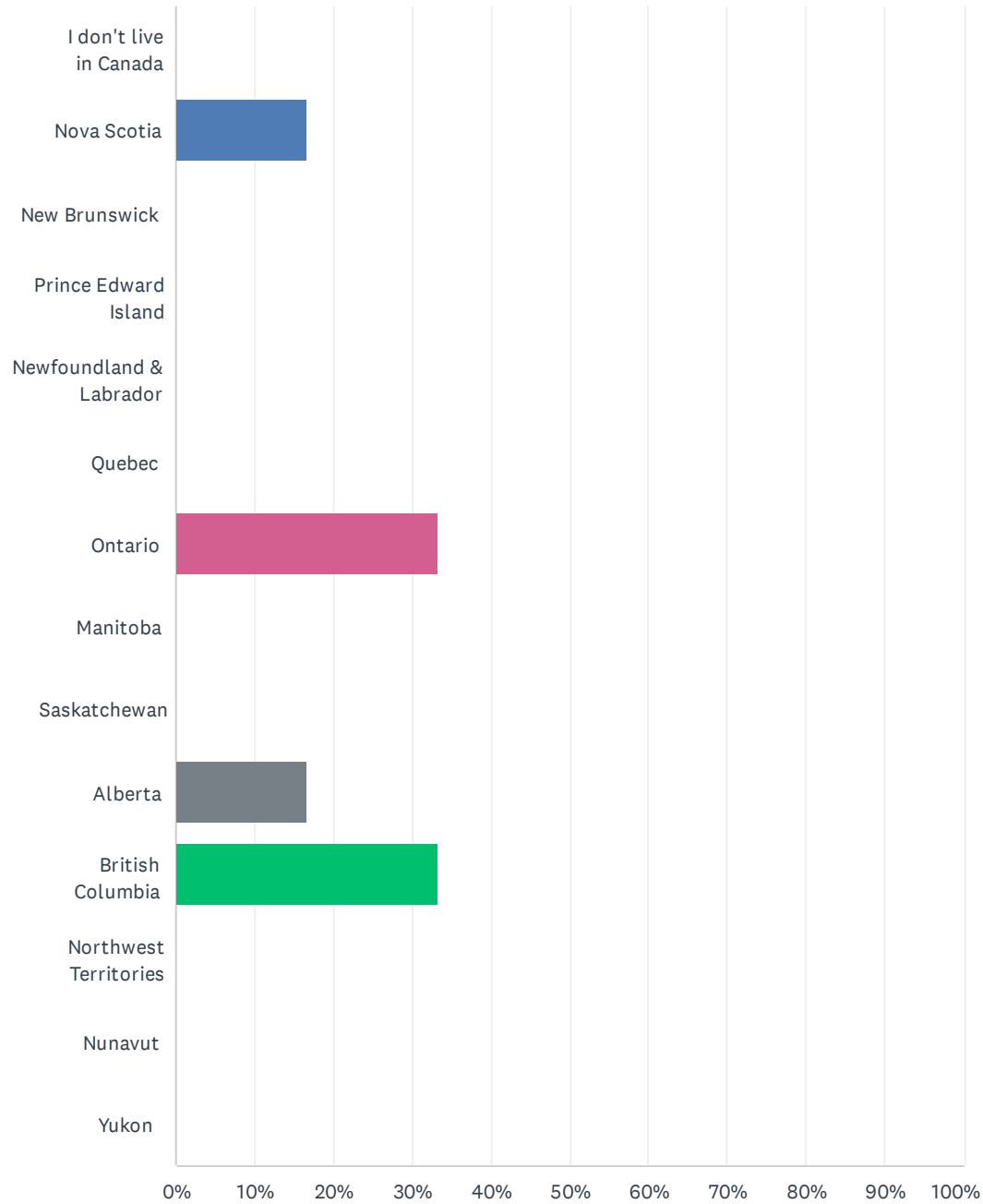
Answered: 6 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	100.00%	6
No	0.00%	0
TOTAL		6

## Q2 If you are a resident of Canada, in which province or territory do you reside?

Answered: 6 Skipped: 0



ANSWER CHOICES	RESPONSES	
I don't live in Canada	0.00%	0
Nova Scotia	16.67%	1
New Brunswick	0.00%	0
Prince Edward Island	0.00%	0
Newfoundland & Labrador	0.00%	0
Quebec	0.00%	0
Ontario	33.33%	2
Manitoba	0.00%	0
Saskatchewan	0.00%	0
Alberta	16.67%	1
British Columbia	33.33%	2
Northwest Territories	0.00%	0
Nunavut	0.00%	0
Yukon	0.00%	0
<b>TOTAL</b>		<b>6</b>

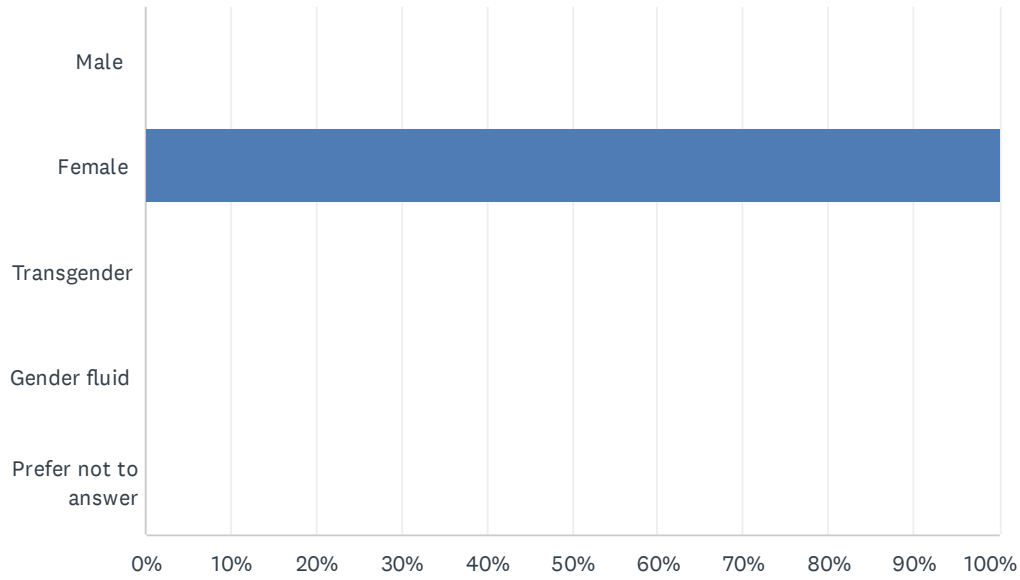
### Q3 If not a resident of Canada, in which country do you live?

Answered: 0 Skipped: 6

#	RESPONSES	DATE
	There are no responses.	

## Q4 What gender do you identify as?

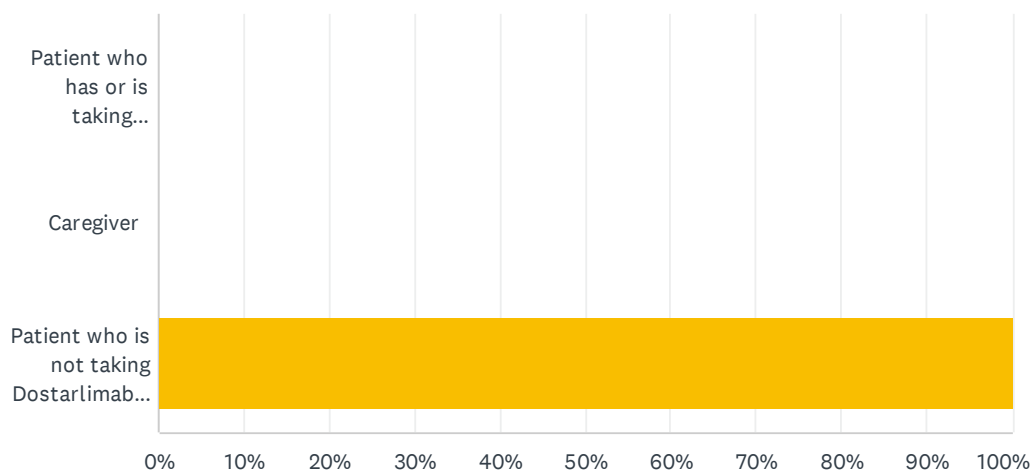
Answered: 6 Skipped: 0



ANSWER CHOICES	RESPONSES
Male	0.00% 0
Female	100.00% 6
Transgender	0.00% 0
Gender fluid	0.00% 0
Prefer not to answer	0.00% 0
<b>TOTAL</b>	<b>6</b>

## Q5 Are you a patient or a caregiver?

Answered: 6 Skipped: 0



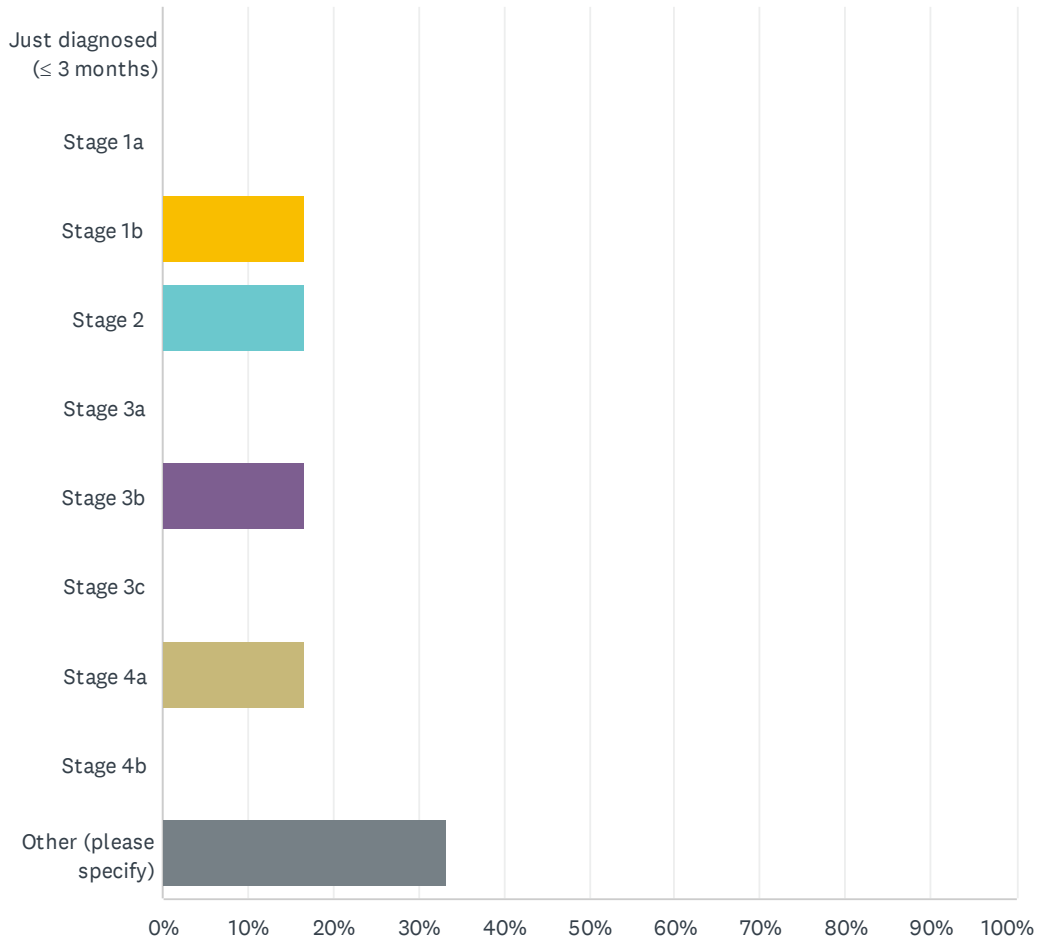
ANSWER CHOICES	RESPONSES
Patient who has or is taking Dostarlimab	0.00% 0
Caregiver	0.00% 0
Patient who is not taking Dostarlimab (please specify treatment)	100.00% 6
<b>TOTAL</b>	<b>6</b>

#	PATIENT WHO IS NOT TAKING DOSTARLIMAB (PLEASE SPECIFY TREATMENT)	DATE
1	I am NED and on no drugs	10/31/2023 7:15 PM
2	niraparib	10/29/2023 3:29 PM
3	Exmethestane	10/29/2023 1:28 PM
4	none in remission	10/28/2023 2:53 PM
5	Had taxol/carboplatin	10/28/2023 11:57 AM
6	Hysterectomy and brachytherapy	10/28/2023 11:55 AM



## Q6 What is the stage of your endometrial cancer?

Answered: 6 Skipped: 0

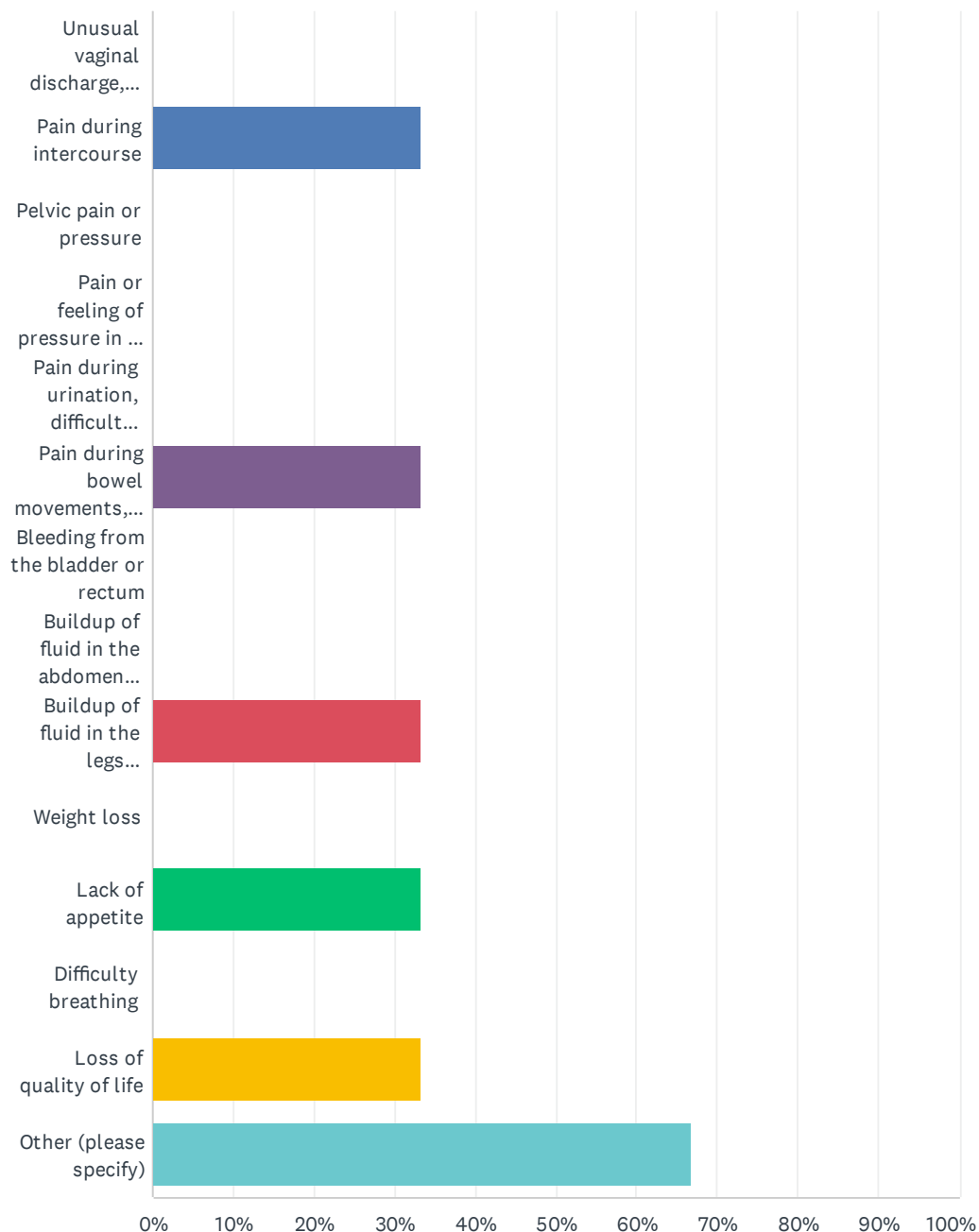


ANSWER CHOICES	RESPONSES	
Just diagnosed (≤ 3 months)	0.00%	0
Stage 1a	0.00%	0
Stage 1b	16.67%	1
Stage 2	16.67%	1
Stage 3a	0.00%	0
Stage 3b	16.67%	1
Stage 3c	0.00%	0
Stage 4a	16.67%	1
Stage 4b	0.00%	0
Other (please specify)	33.33%	2
<b>TOTAL</b>		<b>6</b>

#	OTHER (PLEASE SPECIFY)	DATE
1	mine was breast cancer	10/29/2023 1:28 PM
2	Do not have this type of cancer	10/28/2023 2:53 PM

### Q7 What are the symptoms or problems you experience with endometrial cancer that affect your quality of life (such as your day-to-day living)? Please check all that apply.

Answered: 3 Skipped: 3

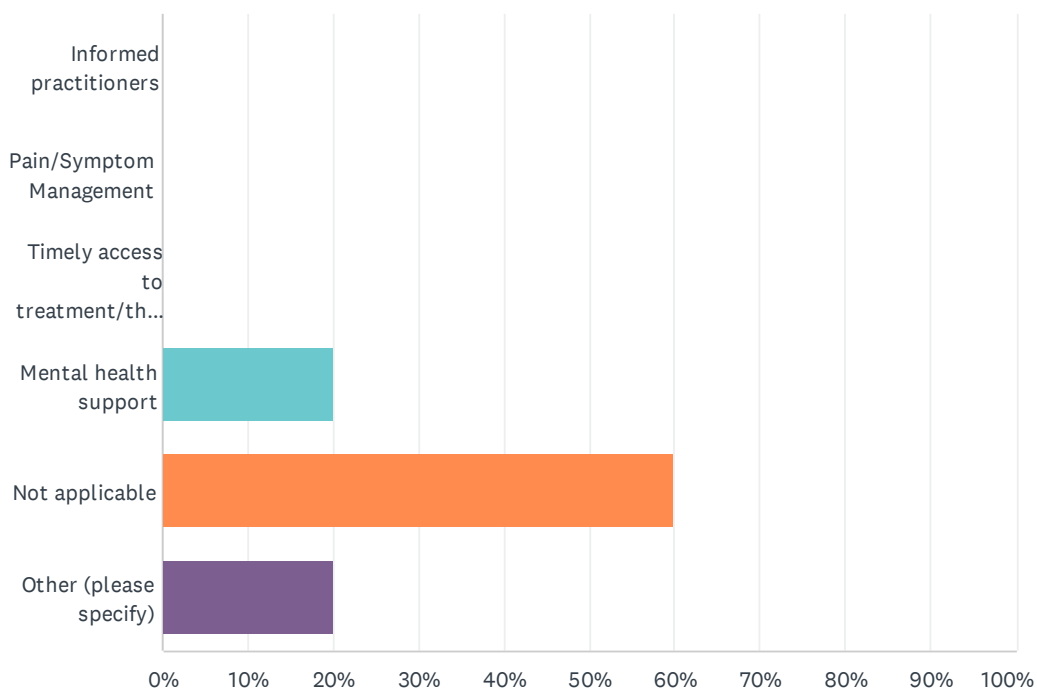


ANSWER CHOICES	RESPONSES
Unusual vaginal discharge, which can be foul smelling, pus-like, or blood-tinged	0.00% 0
Pain during intercourse	33.33% 1
Pelvic pain or pressure	0.00% 0
Pain or feeling of pressure in the lower abdomen, back, or legs	0.00% 0
Pain during urination, difficult urination, or blood in the urine	0.00% 0
Pain during bowel movements, difficult bowel movements, or blood in the stool	33.33% 1
Bleeding from the bladder or rectum	0.00% 0
Buildup of fluid in the abdomen (Ascites)	0.00% 0
Buildup of fluid in the legs (Lymphedema)	33.33% 1
Weight loss	0.00% 0
Lack of appetite	33.33% 1
Difficulty breathing	0.00% 0
Loss of quality of life	33.33% 1
Other (please specify)	66.67% 2
Total Respondents: 3	

#	OTHER (PLEASE SPECIFY)	DATE
1	n/a	10/29/2023 1:28 PM
2	Tired when I get up, lack of stamina	10/28/2023 11:57 AM

## Q8 Are there any needs in your current therapy that are not yet being met?

Answered: 5 Skipped: 1

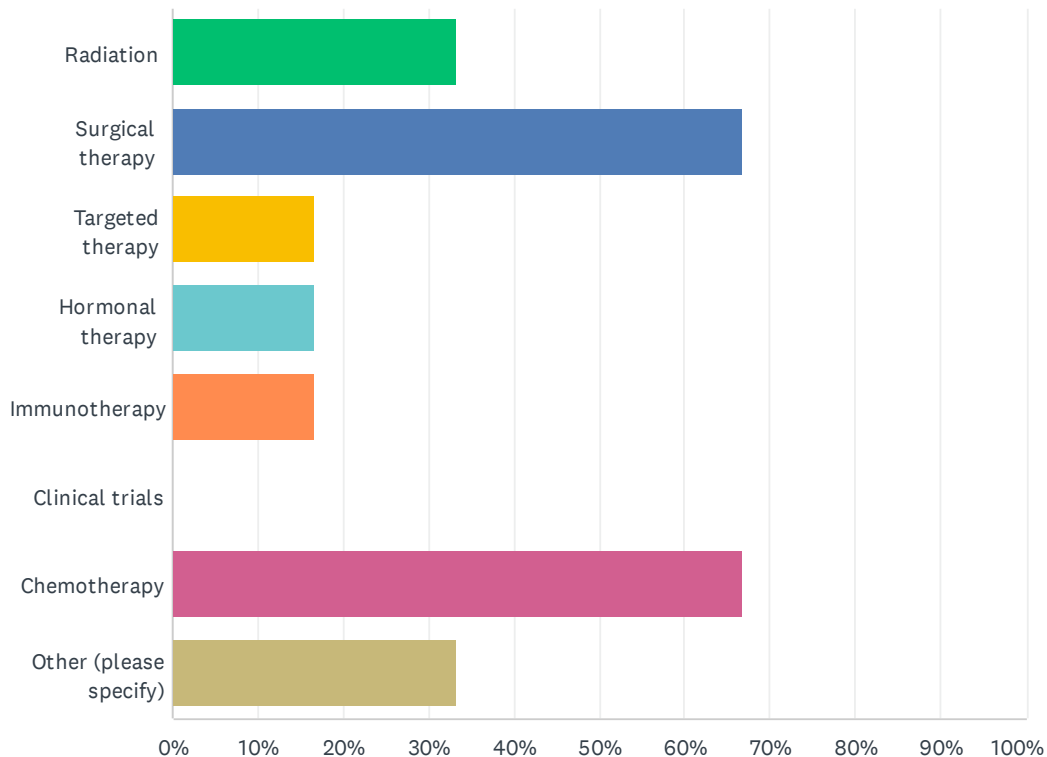


ANSWER CHOICES	RESPONSES
Informed practitioners	0.00% 0
Pain/Symptom Management	0.00% 0
Timely access to treatment/therapy	0.00% 0
Mental health support	20.00% 1
Not applicable	60.00% 3
Other (please specify)	20.00% 1
Total Respondents: 5	

#	OTHER (PLEASE SPECIFY)	DATE
1	Finished checkups but there was never enough time allotted for checkups	10/28/2023 11:57 AM

### Q9 What drug therapies or other types of treatments are you currently using, or did you use, to treat your disease? Please check all that apply.

Answered: 6 Skipped: 0



ANSWER CHOICES	RESPONSES
Radiation	33.33% 2
Surgical therapy	66.67% 4
Targeted therapy	16.67% 1
Hormonal therapy	16.67% 1
Immunotherapy	16.67% 1
Clinical trials	0.00% 0
Chemotherapy	66.67% 4
Other (please specify)	33.33% 2
Total Respondents: 6	

#	OTHER (PLEASE SPECIFY)	DATE
1	I took a pill ( don't know the name of it) for 5 years.	10/28/2023 2:53 PM
2	Accupuncture, massage therapy	10/28/2023 11:57 AM

### Q10 Is there an aspect of your disease that, to you, is more important to control than others? Please explain.

Answered: 4 Skipped: 2

#	RESPONSES	DATE
1	Recurrence prevention	10/29/2023 3:29 PM
2	no	10/29/2023 1:28 PM
3	I had Brest Cancer that went into the Lymph glans/nodes under my arm	10/28/2023 2:53 PM
4	Kicked out of cancer centre after treatment finished. Should have been assigned a nurse for communication. Had to do all my own research to get better. Needed better after care.	10/28/2023 11:57 AM

## Q11 What adverse effects, if any, were caused by taking Dostarlimab? Please check all that apply.

Answered: 0 Skipped: 6

 No matching responses.

ANSWER CHOICES	RESPONSES
Anemia	0.00% 0
Fatigue	0.00% 0
Nausea	0.00% 0
Rash	0.00% 0
Diarrhea	0.00% 0
Vomiting	0.00% 0
Other (please specify)	0.00% 0
Total Respondents: 0	

#	OTHER (PLEASE SPECIFY)	DATE
	There are no responses.	



**Q12 Were these adverse effects of being treated with Dostarlimab tolerated (i.e. symptoms were managed with other treatment/medications and you did not have to discontinue use of Dostarlimab)? If yes, how did you manage them?**

Answered: 0 Skipped: 6

 No matching responses.

ANSWER CHOICES	RESPONSES
No	0.00% 0
Yes	0.00% 0
TOTAL	0

#	YES	DATE
	There are no responses.	

## Q13 How were you able to gain access to Dostarlimab? i.e. clinical trial, private insurance

Answered: 0 Skipped: 6

#	RESPONSES	DATE
	There are no responses.	

### Q14 In your own words, please describe the advantages and disadvantages of Dostarlimab and how they made an impact on your life.

Answered: 0 Skipped: 6

#	RESPONSES	DATE
	There are no responses.	

**Q15 Would you recommend that Dostarlimab be made available to all patients who qualify for it? 1 being 'Absolutely Not' and 5 being 'Yes, immediately'.**

Answered: 0 Skipped: 6

 No matching responses.

	1	2	3	4	5	TOTAL	WEIGHTED AVERAGE
(no label)	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0	0.00

## Q16 In comparison to other therapies, how was your treatment experience with Dostarlimab in treating your endometrial cancer?

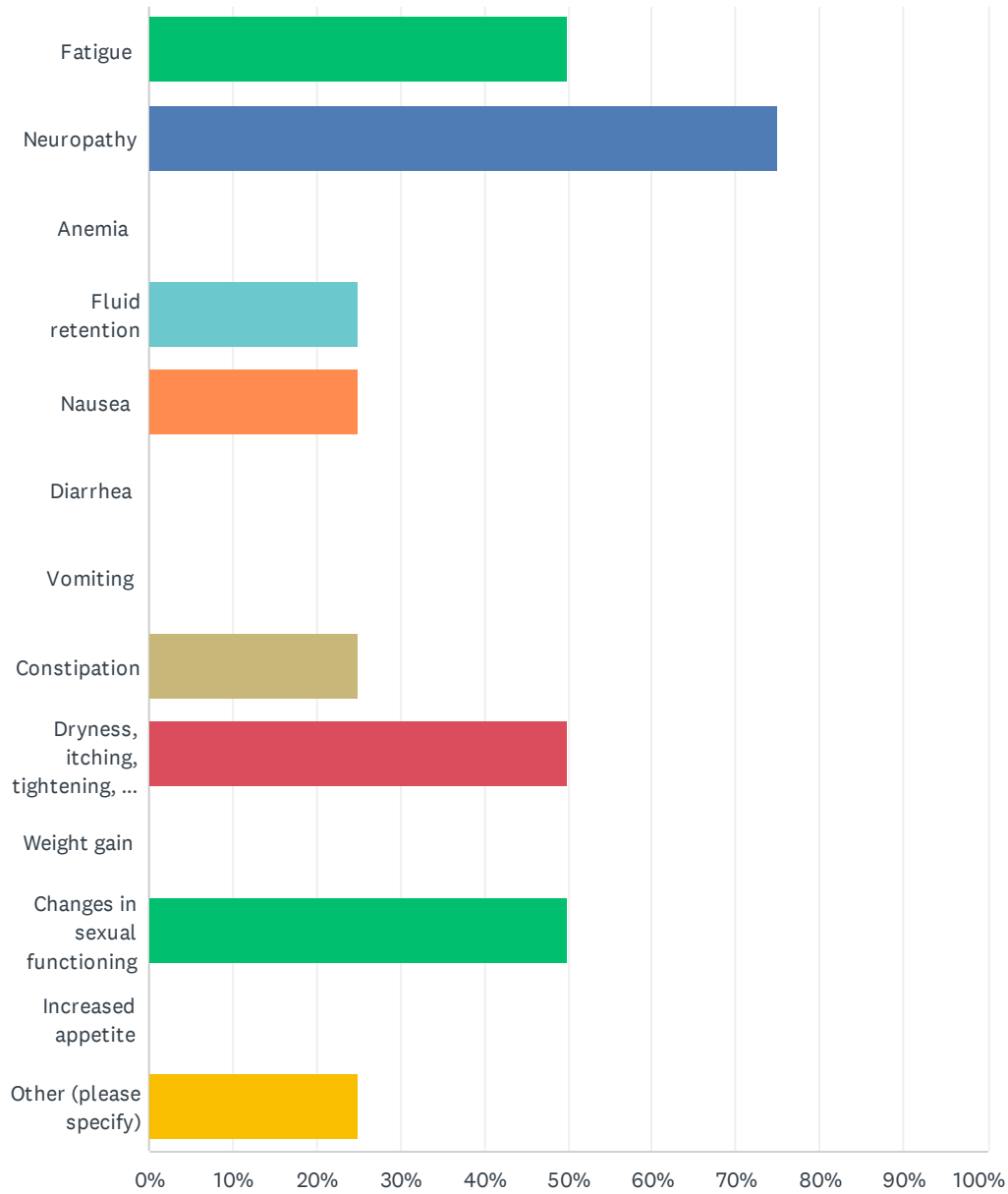
Answered: 0 Skipped: 6

 No matching responses.

	MUCH BETTER	LITTLE OR NO DIFFERENCE	MUCH WORSE	TOTAL	WEIGHTED AVERAGE
Symptom management	0.00% 0	0.00% 0	0.00% 0	0	0.00
Side effects	0.00% 0	0.00% 0	0.00% 0	0	0.00
Ease of use	0.00% 0	0.00% 0	0.00% 0	0	0.00
Disease progression	0.00% 0	0.00% 0	0.00% 0	0	0.00

### Q17 What adverse effects, if any, were caused by your current treatments? Please check all that apply.

Answered: 4 Skipped: 2



Canadian Cancer Survivor Network Questionnaire for Patient and Caregiver Input on DOSTARLIMAB (Jemperli)

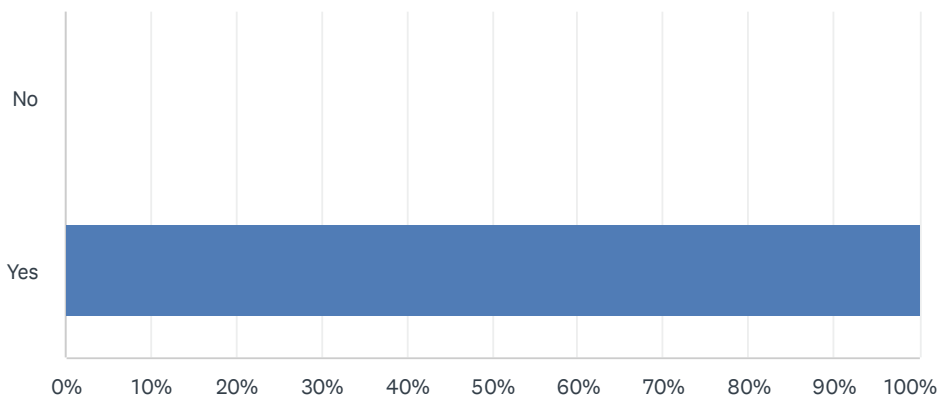
SurveyMonkey

ANSWER CHOICES	RESPONSES	
Fatigue	50.00%	2
Neuropathy	75.00%	3
Anemia	0.00%	0
Fluid retention	25.00%	1
Nausea	25.00%	1
Diarrhea	0.00%	0
Vomiting	0.00%	0
Constipation	25.00%	1
Dryness, itching, tightening, and burning in the vagina	50.00%	2
Weight gain	0.00%	0
Changes in sexual functioning	50.00%	2
Increased appetite	0.00%	0
Other (please specify)	25.00%	1
Total Respondents: 4		

#	OTHER (PLEASE SPECIFY)	DATE
1	Chemo brain	10/28/2023 11:57 AM

**Q18 Were the adverse effects of your current treatment tolerated (i.e. symptoms were managed with other treatment/medications and you did not have to discontinue use of Dostarlimab)? If yes, how did you manage them?**

Answered: 2 Skipped: 4



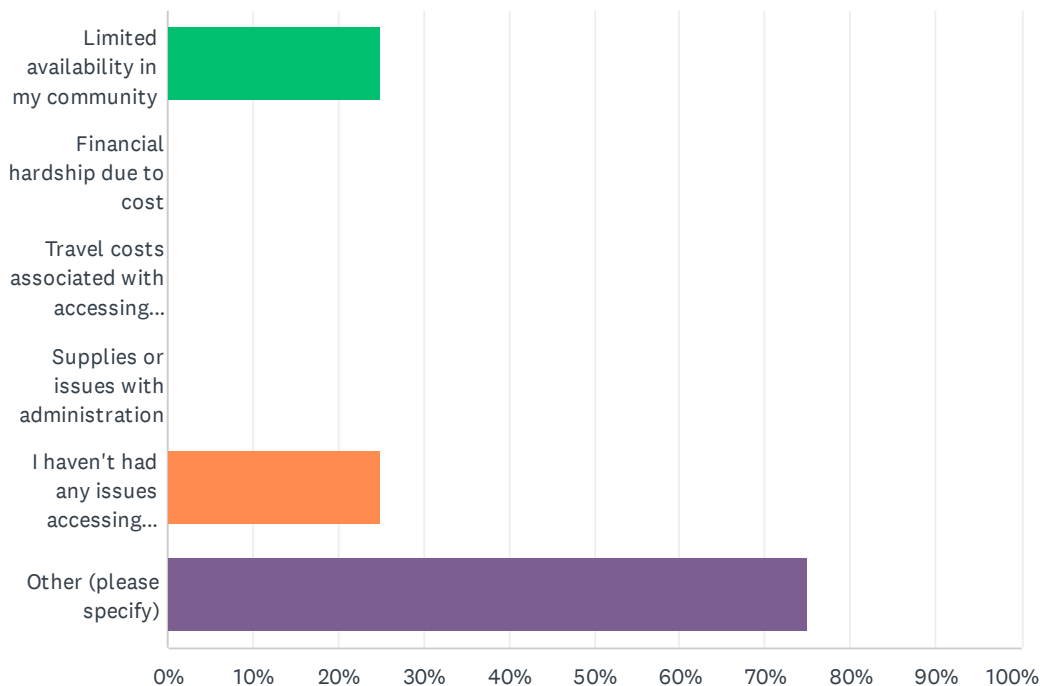
ANSWER CHOICES	RESPONSES
No	0.00% 0
Yes	100.00% 2
<b>TOTAL</b>	<b>2</b>

#	YES	DATE
1	half dosage; nausea occasionally; prochlorperazine	10/29/2023 3:29 PM
2	N/a	10/28/2023 11:57 AM



### Q19 Have you had issues accessing any therapies? If so, what issues have you experienced? Please check all that apply.

Answered: 4 Skipped: 2



ANSWER CHOICES	RESPONSES
Limited availability in my community	25.00% 1
Financial hardship due to cost	0.00% 0
Travel costs associated with accessing therapy/treatment	0.00% 0
Supplies or issues with administration	0.00% 0
I haven't had any issues accessing therapy	25.00% 1
Other (please specify)	75.00% 3
Total Respondents: 4	

#	OTHER (PLEASE SPECIFY)	DATE
1	Any clinical trial using Dostarlimab with niraparib was never mentioned by the clinician	10/29/2023 3:29 PM
2	Had difficulty getting a biopsy at my licsl hospital -cancelled twice	10/28/2023 11:57 AM
3	Driving from home to Clinic in winter weather	10/28/2023 11:55 AM

## Q20 If a friend asked you how you are managing at this stage in your treatment, what would you tell them? Please fill out the fields for the treatments you have/are receiving.

Answered: 3 Skipped: 3

ANSWER CHOICES	RESPONSES
How are you managing with surgery?	100.00% 3
How are you managing with radiation (internal radiation, brachytherapy, or external beam radiation)?	33.33% 1
How are you managing with hormone therapy (progestins, tamoxifen, LHRH agonists, aromatase inhibitors)?	33.33% 1
How are you managing with chemotherapy (paclitaxel, carboplatin, doxorubicin, cisplatin, docetaxel)?	66.67% 2
How are you managing with immunotherapy (pembrolizumab)?	0.00% 0
How are you managing with targeted therapy (lenvatinib, bevacizumab, mTOR inhibitors)?	0.00% 0

#	HOW ARE YOU MANAGING WITH SURGERY?	DATE
---	------------------------------------	------

1	Managed well	10/29/2023 3:29 PM
2	ok	10/29/2023 1:28 PM
3	Some bowel oain	10/28/2023 11:57 AM

#	HOW ARE YOU MANAGING WITH RADIATION (INTERNAL RADIATION, BRACHYTHERAPY, OR EXTERNAL BEAM RADIATION)?	DATE
---	--	------

1	ok	10/29/2023 1:28 PM
---	----	--------------------

#	HOW ARE YOU MANAGING WITH HORMONE THERAPY (PROGESTINS, TAMOXIFEN, LHRH AGONISTS, AROMATASE INHIBITORS)?	DATE
---	---	------

1	Ok	10/29/2023 1:28 PM
---	----	--------------------

#	HOW ARE YOU MANAGING WITH CHEMOTHERAPY (PACLITAXEL, CARBOPLATIN, DOXORUBICIN, CISPLATIN, DOCETAXEL)?	DATE
---	--	------

1	Was tough; much nausea and contipation	10/29/2023 3:29 PM
2	Affects my thinking, loss of stamina, fatigue	10/28/2023 11:57 AM

#	HOW ARE YOU MANAGING WITH IMMUNOTHERAPY (PEMBROLIZUMAB)?	DATE
---	--	------

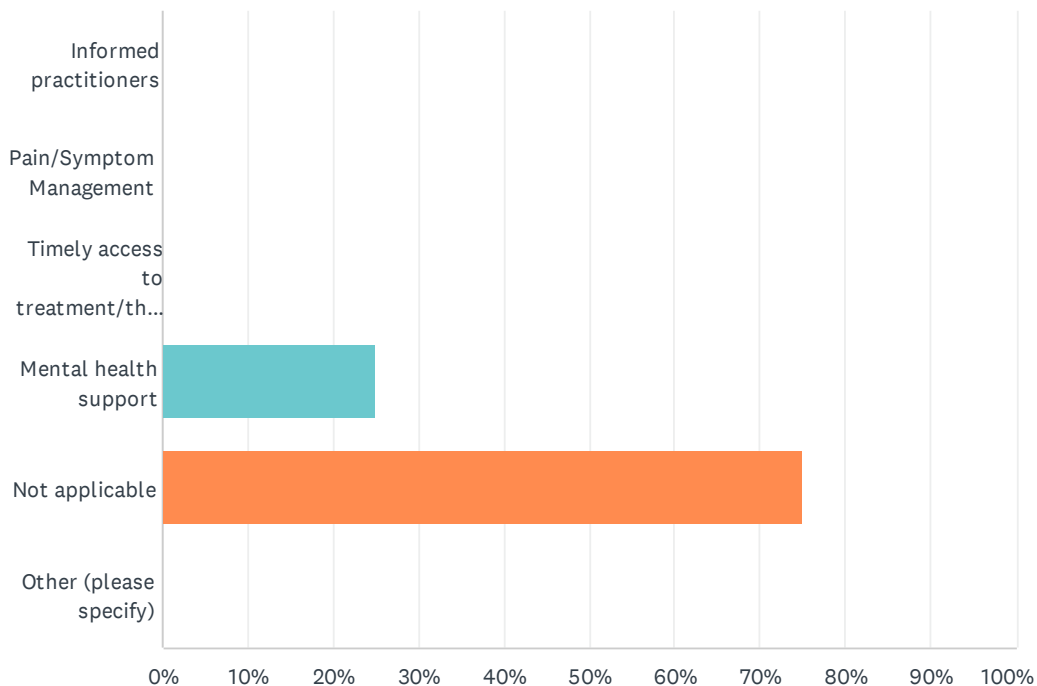
	There are no responses.	
--	-------------------------	--

#	HOW ARE YOU MANAGING WITH TARGETED THERAPY (LENVATINIB, BEVACIZUMAB, MTOR INHIBITORS)?	DATE
---	--	------

	There are no responses.	
--	-------------------------	--

## Q21 Are there any needs in your current treatment that are not yet being met?

Answered: 4 Skipped: 2

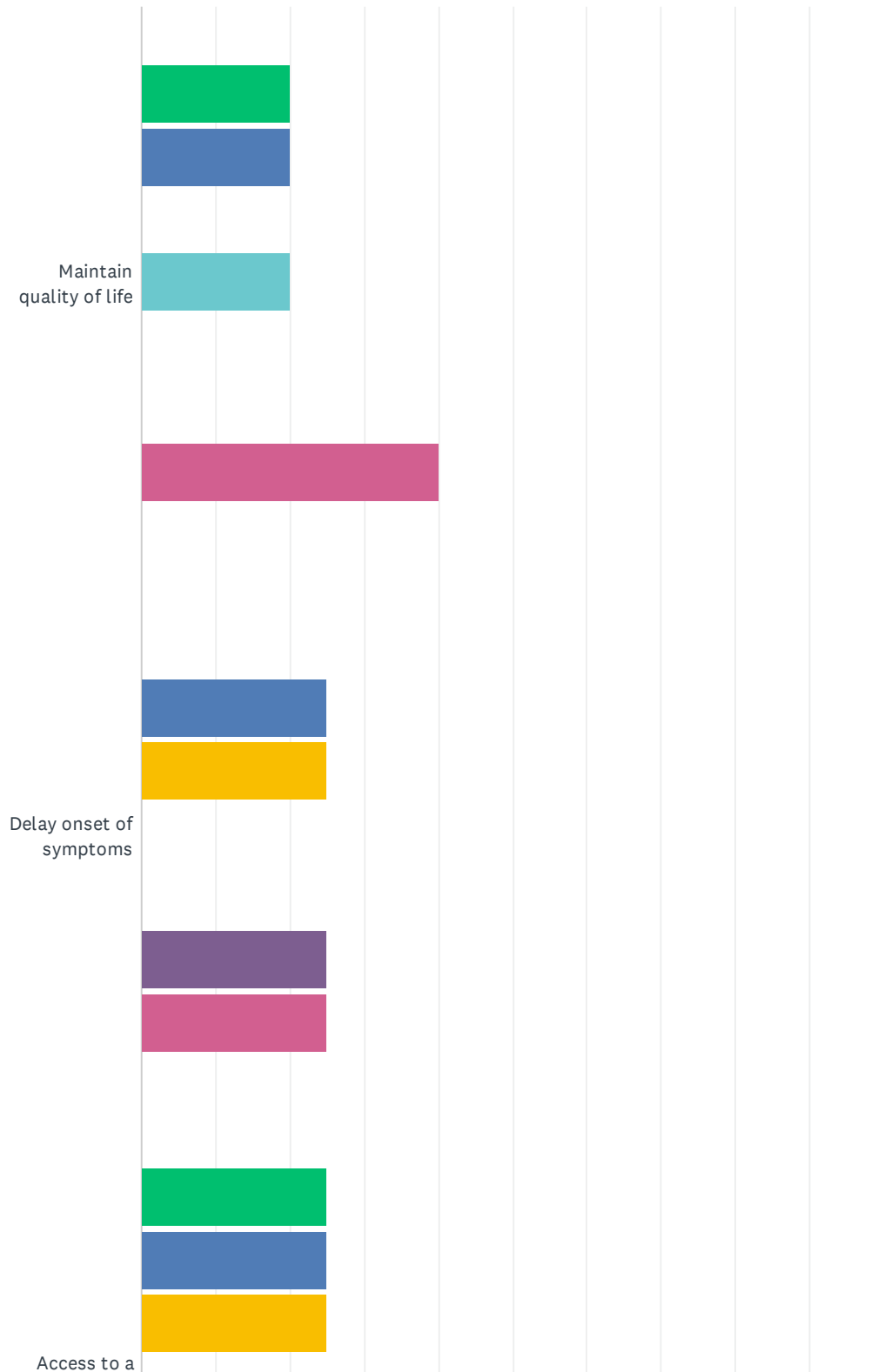


ANSWER CHOICES	RESPONSES
Informed practitioners	0.00% 0
Pain/Symptom Management	0.00% 0
Timely access to treatment/therapy	0.00% 0
Mental health support	25.00% 1
Not applicable	75.00% 3
Other (please specify)	0.00% 0
Total Respondents: 4	

#	OTHER (PLEASE SPECIFY)	DATE
	There are no responses.	

Q22 Which of the following issues would you hope that a new treatment would address to manage your disease? Please rate the options from most important (1) to least important (7).

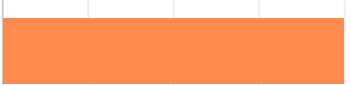
Answered: 5 Skipped: 1



new option for treatment

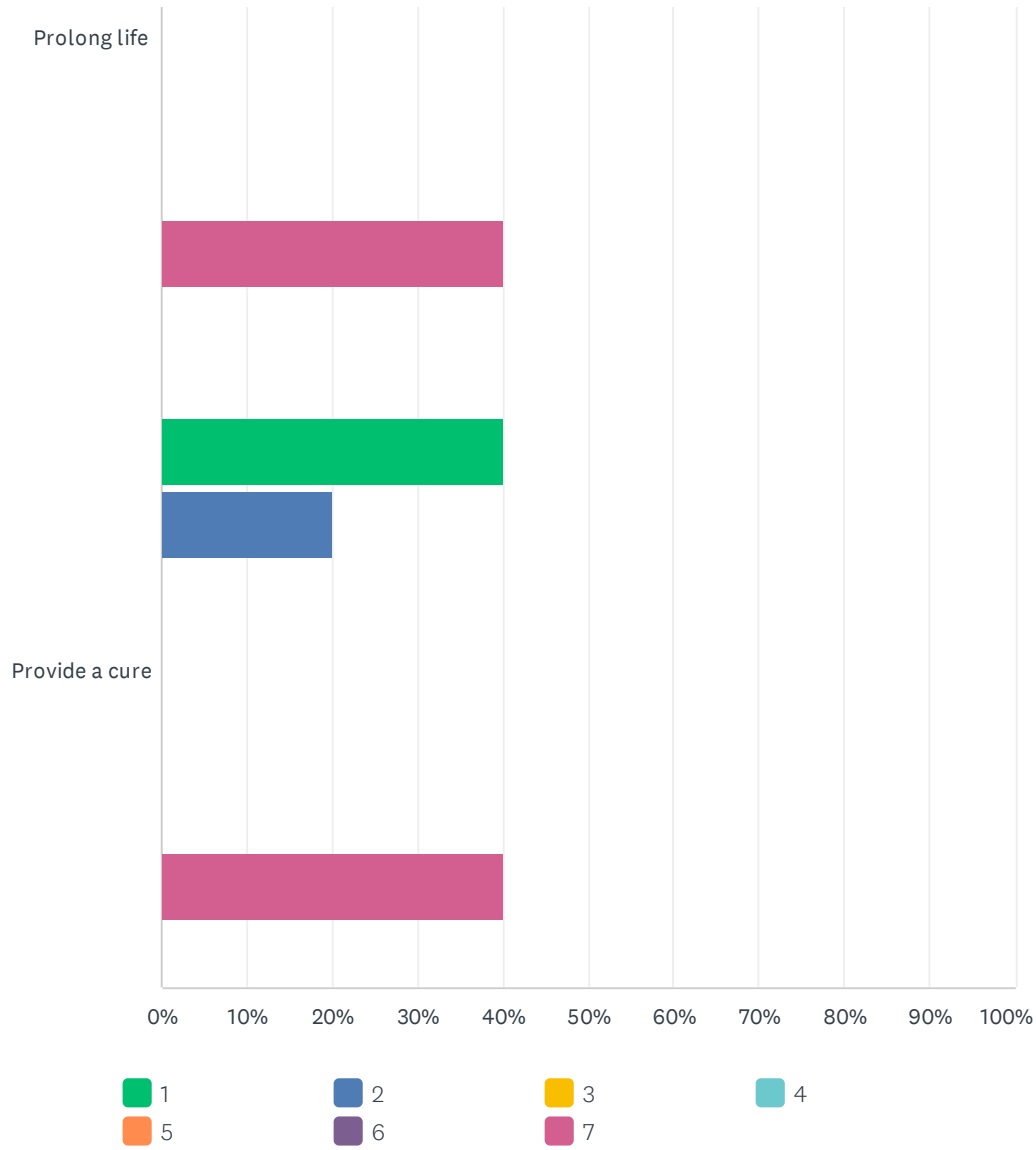


Reduce side effects from current...



Ease of use

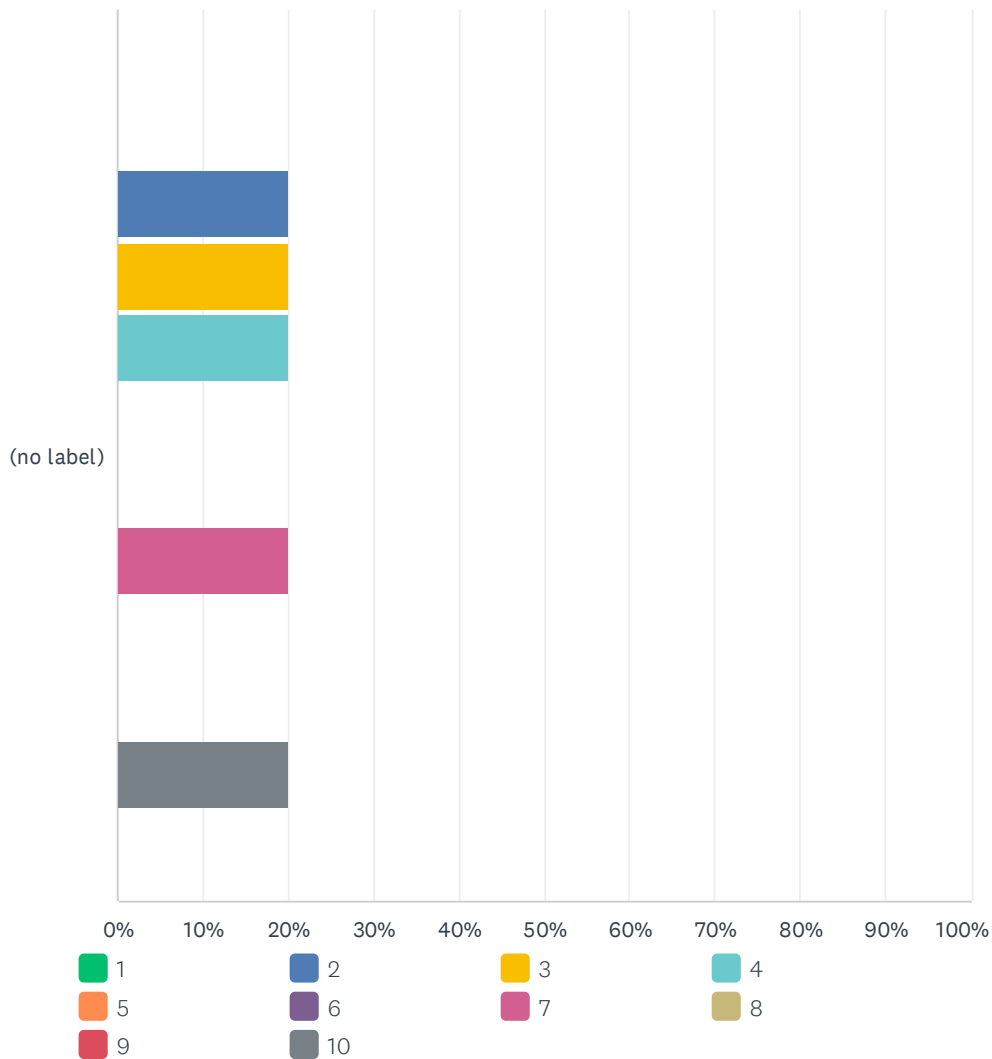




	1	2	3	4	5	6	7	TOTAL	WEIGHTED AVERAGE
Maintain quality of life	20.00% 1	20.00% 1	0.00% 0	20.00% 1	0.00% 0	0.00% 0	40.00% 2	5	4.20
Delay onset of symptoms	0.00% 0	25.00% 1	25.00% 1	0.00% 0	0.00% 0	25.00% 1	25.00% 1	4	4.50
Access to a new option for treatment	25.00% 1	25.00% 1	25.00% 1	0.00% 0	25.00% 1	0.00% 0	0.00% 0	4	2.75
Reduce side effects from current medications or treatments	20.00% 1	0.00% 0	40.00% 2	0.00% 0	40.00% 2	0.00% 0	0.00% 0	5	3.40
Ease of use	20.00% 1	0.00% 0	20.00% 1	0.00% 0	0.00% 0	0.00% 0	60.00% 3	5	5.00
Prolong life	60.00% 3	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0.00% 0	40.00% 2	5	3.40
Provide a cure	40.00% 2	20.00% 1	0.00% 0	0.00% 0	0.00% 0	0.00% 0	40.00% 2	5	3.60

**Q23 On a scale of 1-10, with 1 being “no side effects” and 10 being “significant side effects”, if you were to consider taking a new therapy for your cancer, what severity of side effects would you be willing to tolerate in order to extend survival by 2 months, after having been told there is no other available treatment? For example, side effects such as: nausea, fatigue, vomiting, diarrhea.**

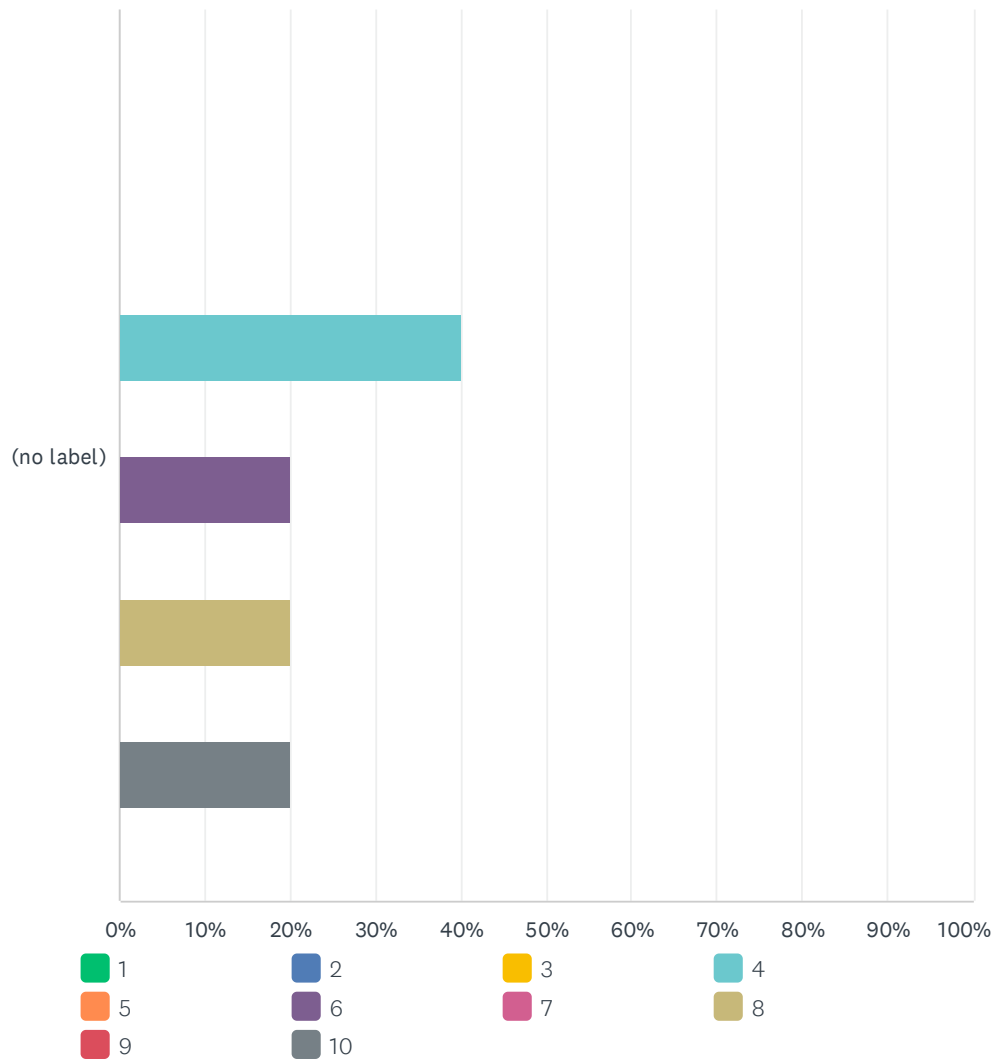
Answered: 5 Skipped: 1



	1	2	3	4	5	6	7	8	9	10	TOTAL	WEIGHTED AVERAGE
(no label)	0.00%	20.00%	20.00%	20.00%	0.00%	0.00%	20.00%	0.00%	0.00%	20.00%	5	5.20
	0	1	1	1	0	0	1	0	0	1		

**Q24** On a scale of 1-10, with 1 being “no side effects” and 10 being “significant side effects”, if you were to consider taking a new therapy for your cancer, what severity of side effects would you be willing to tolerate in order to extend survival by 6 months, after having been told there is no other available treatment? For example, side effects such as: nausea, fatigue, vomiting, diarrhea.

Answered: 5 Skipped: 1

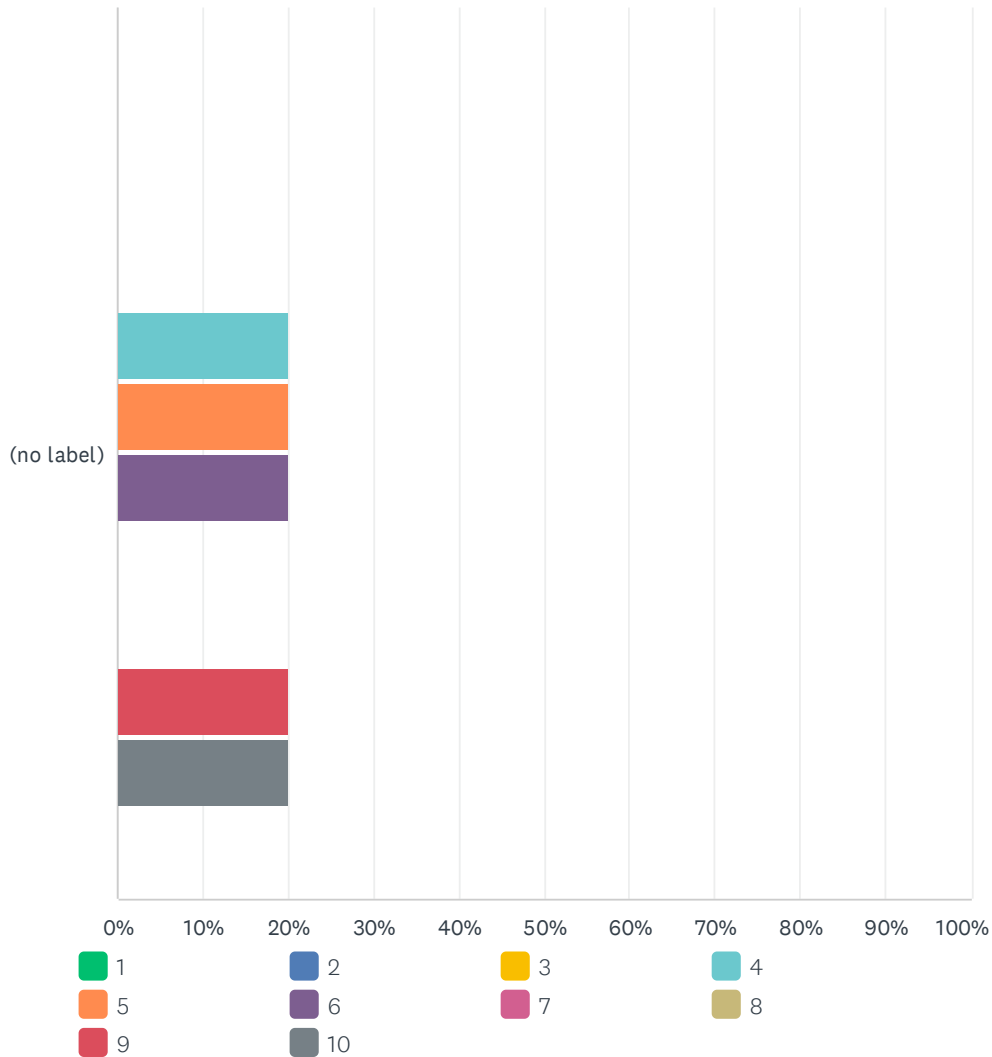


	1	2	3	4	5	6	7	8	9	10	TOTAL	WEIGHTED AVERAGE
(no label)	0.00% 0	0.00% 0	0.00% 0	40.00% 2	0.00% 0	20.00% 1	0.00% 0	20.00% 1	0.00% 0	20.00% 1	5	6.40



**Q25 On a scale of 1-10, with 1 being “no side effects” and 10 being “significant side effects”, if you were to consider taking a new therapy for your cancer, what severity of side effects would you be willing to tolerate in order to extend survival by 1 year, after having been told there is no other available treatment? For example, side effects such as: nausea, fatigue, vomiting, diarrhea.**

Answered: 5 Skipped: 1



	1	2	3	4	5	6	7	8	9	10	TOTAL	WEIGHTED AVERAGE
(no label)	0.00%	0.00%	0.00%	20.00%	20.00%	20.00%	0.00%	0.00%	20.00%	20.00%	5	6.80
	0	0	0	1	1	1	0	0	1	1		

## Q26 What considerations do you make when it comes to balancing the advantages and disadvantages of a treatment?

Answered: 3 Skipped: 3

#	RESPONSES	DATE
1	Quality of life, energy	10/29/2023 3:29 PM
2	Longevity, How severe the other side effects are.	10/29/2023 1:28 PM
3	Quality of life, extending my life	10/28/2023 11:57 AM

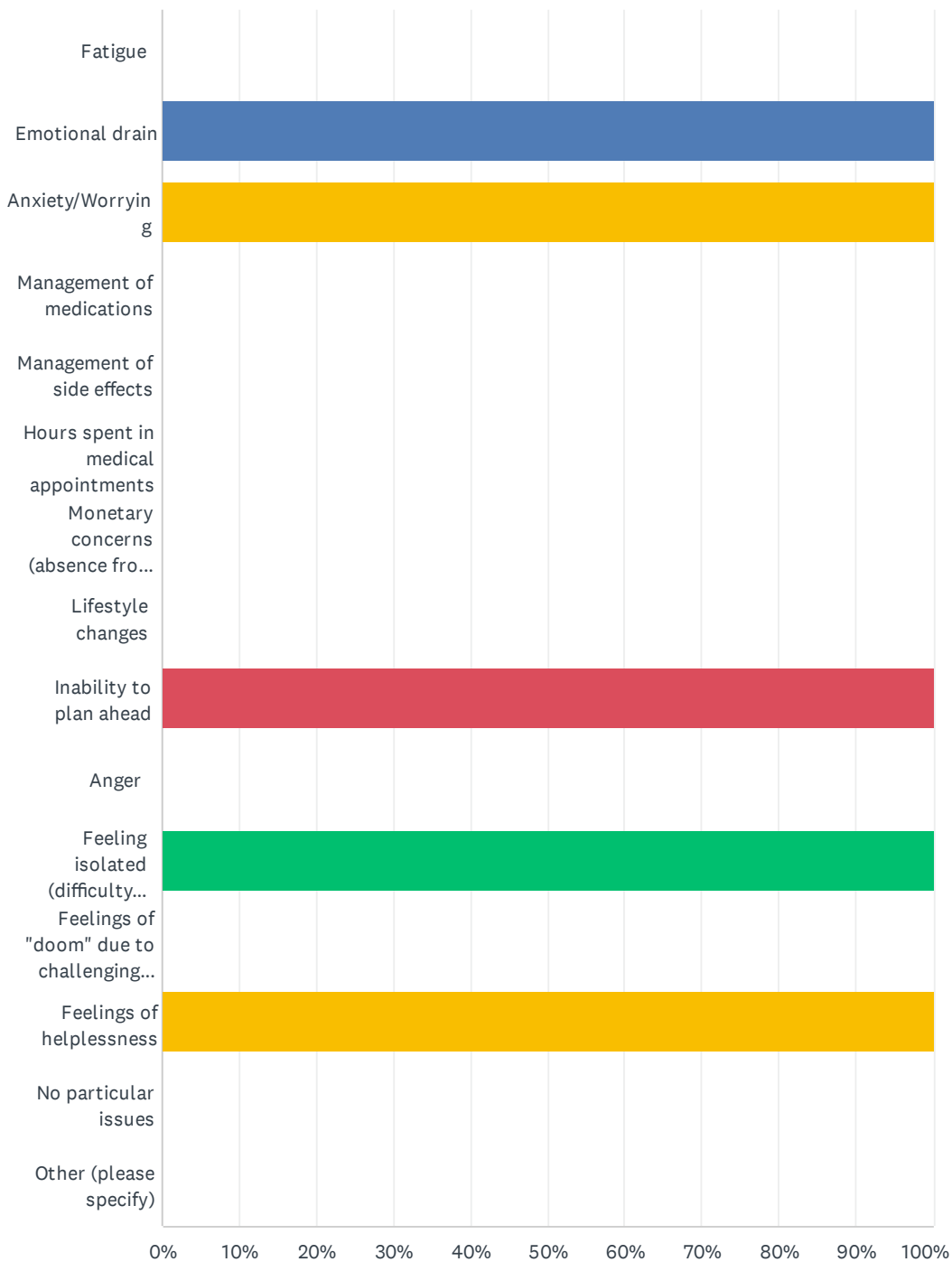
## Q27 Is there anything else you would like to share with us about your cancer journey?

Answered: 3 Skipped: 3

#	RESPONSES	DATE
1	I was blessed to have unlimited support through the Cancer foundation of Canada. My radiation went very well. Everyone one was so helpful. I just felt very well cared for everywhere.	10/29/2023 1:28 PM
2	Cancer treatment care was great. Big drop of in care between my gp and gyne doctors. No help for after care.	10/28/2023 11:57 AM
3	I was referred for genetic testing because of family colo-rectal cancer history. However my tumour test was not MSI-High. A wise genetic counsellor encouraged me to have the DNA test regardless which I did. Results were positive for Lynch Syndrome. Subsequently my surviving brother and one of my 2 daughters have also tested positive. A second MSI Tumour test requested by the the genetic counsellor confirmed the original test results. This was not the first time in my now 35 year long cancer journey that I have had a "false negative" on a test. This can be disconcerting knowledge to have lived with as a now 80 year old.	10/28/2023 11:55 AM

## Q28 What are the issues you encounter or have encountered as a caregiver for someone with endometrial cancer? Check all that apply.

Answered: 1 Skipped: 5

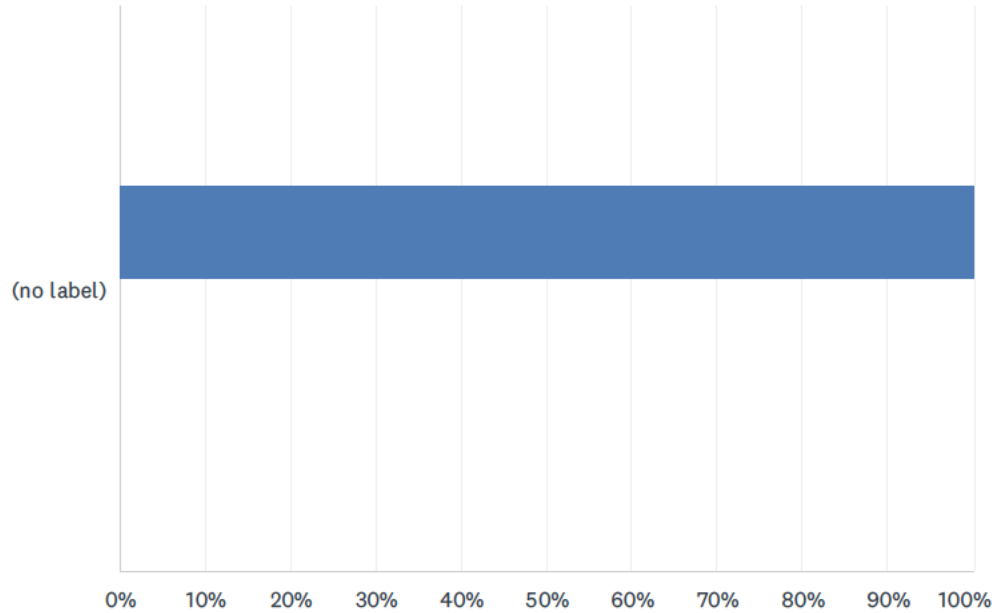


ANSWER CHOICES	RESPONSES
Fatigue	0.00% 0
Emotional drain	100.00% 1
Anxiety/Worrying	100.00% 1
Management of medications	0.00% 0
Management of side effects	0.00% 0
Hours spent in medical appointments	0.00% 0
Monetary concerns (absence from work, driving expenses, etc.)	0.00% 0
Lifestyle changes	0.00% 0
Inability to plan ahead	100.00% 1
Anger	0.00% 0
Feeling isolated (difficulty connecting with friends, geographical remoteness)	100.00% 1
Feelings of "doom" due to challenging prognosis	0.00% 0
Feelings of helplessness	100.00% 1
No particular issues	0.00% 0
Other (please specify)	0.00% 0
Total Respondents: 1	

#	OTHER (PLEASE SPECIFY)	DATE
	There are no responses.	

## Q29 How would you rate the current treatments based on how they address the needs of endometrial cancer patients?

Answered: 1 Skipped: 5



■ Excellent
 ■ Good
 ■ Poor
 ■ Very Poor

	EXCELLENT	GOOD	POOR	VERY POOR	TOTAL	WEIGHTED AVERAGE
(no label)	0.00% 0	100.00% 1	0.00% 0	0.00% 0	1	2.00

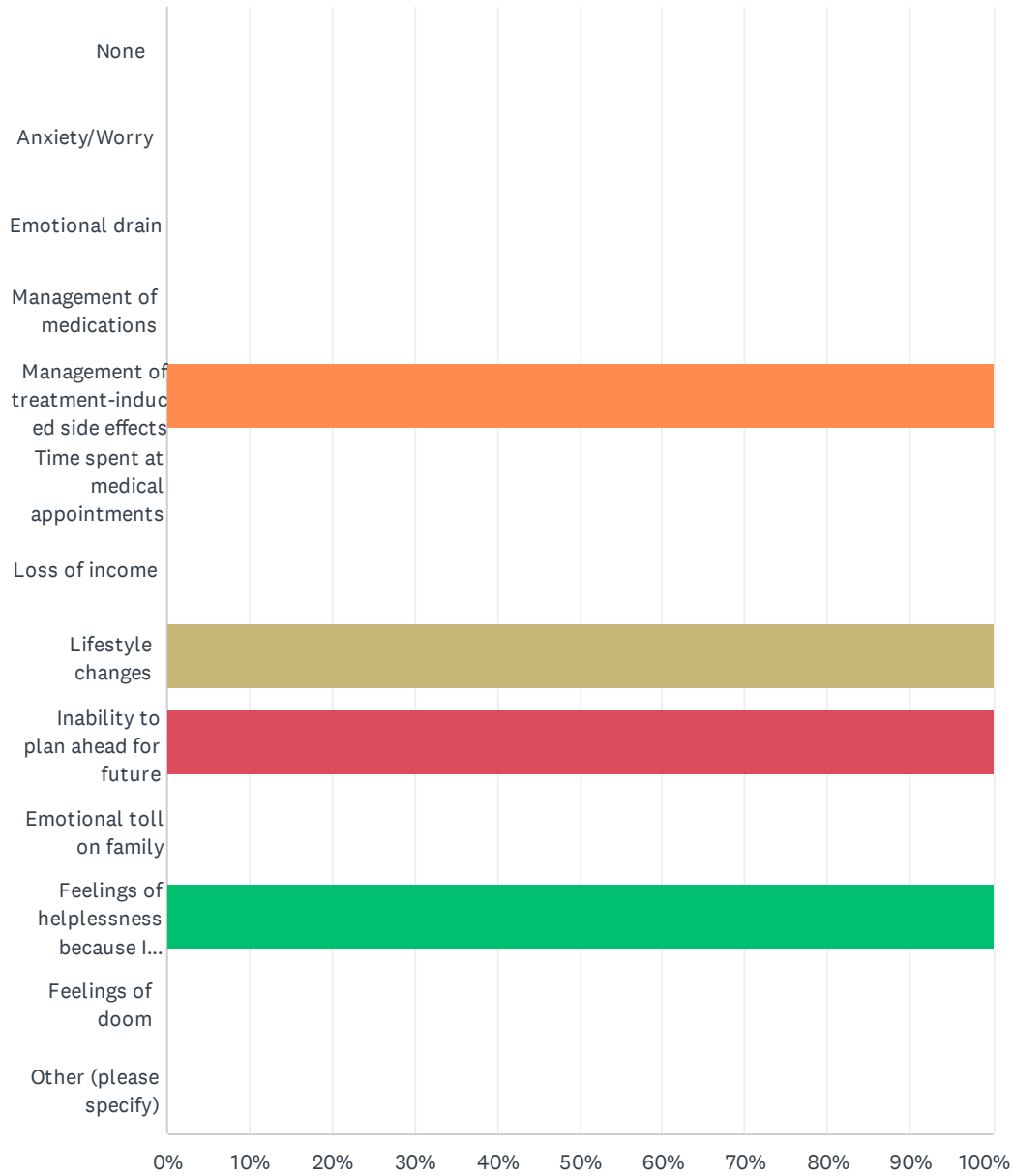
## Q30 How has caring for someone with endometrial cancer affected your daily routine or lifestyle?

Answered: 0 Skipped: 6

#	RESPONSES	DATE
	There are no responses.	

### Q31 What are the most challenging adverse effects related to your loved one and their current therapy or treatment?

Answered: 1 Skipped: 5





ANSWER CHOICES	RESPONSES	
None	0.00%	0
Anxiety/Worry	0.00%	0
Emotional drain	0.00%	0
Management of medications	0.00%	0
Management of treatment-induced side effects	100.00%	1
Time spent at medical appointments	0.00%	0
Loss of income	0.00%	0
Lifestyle changes	100.00%	1
Inability to plan ahead for future	100.00%	1
Emotional toll on family	0.00%	0
Feelings of helplessness because I cannot help my loved one feel better	100.00%	1
Feelings of doom	0.00%	0
Other (please specify)	0.00%	0
Total Respondents: 1		

#	OTHER (PLEASE SPECIFY)	DATE
	There are no responses.	

## Q32 What would you most like to see out of a new treatment for patients with endometrial cancer?

Answered: 0 Skipped: 6

#	RESPONSES	DATE
	There are no responses.	

### Q33 Is there anything else that you would like to share with us about your experiences as a caregiver?

Answered: 0 Skipped: 6

#	RESPONSES	DATE
	There are no responses.	

### Q34 If you are interested in being contacted as a patient or a caregiver, to provide further information, please leave your contact information below.

Answered: 2 Skipped: 4

ANSWER CHOICES	RESPONSES
Name	100.00% 2
Company	0.00% 0
Address	0.00% 0
Address 2	0.00% 0
City/Town	0.00% 0
State/Province	0.00% 0
ZIP/Postal Code	0.00% 0
Country	100.00% 2
Email Address	100.00% 2
Phone Number	100.00% 2

#	NAME	DATE
1	[REDACTED]	10/29/2023 3:29 PM
2	[REDACTED]	10/28/2023 11:57 AM
#	COMPANY	DATE
	There are no responses.	
#	ADDRESS	DATE
	There are no responses.	
#	ADDRESS 2	DATE
	There are no responses.	
#	CITY/TOWN	DATE
	There are no responses.	
#	STATE/PROVINCE	DATE
	There are no responses.	
#	ZIP/POSTAL CODE	DATE
	There are no responses.	
#	COUNTRY	DATE
1	canada	10/29/2023 3:29 PM
2	Canada	10/28/2023 11:57 AM
#	EMAIL ADDRESS	DATE
1	[REDACTED]	10/29/2023 3:29 PM
2	[REDACTED]	10/28/2023 11:57 AM

#	PHONE NUMBER	DATE
1	[REDACTED]	10/29/2023 3:29 PM
2	[REDACTED]	10/28/2023 11:57 AM



## **APPENDIX E: DURVALUMAB SOCIAL MEDIA PATIENT EXPERIENCE ACCOUNT**

**May 14, 2019**

I made it! 10th cycle of durvalumab trial completed. Almost a year since my stage 3 cancer diagnosis and I'm still here folks! Received good news today that my tumor continues to shrink and the spots on my lymph nodes have also decreased. And no sign of new disease. Huzzah. Life is good.

[#endometrialcancer](#) [#immunotherapytrial#durvalumab](#) [#thankful](#) [#petermaccallumcancercentre#milestone](#) [#trialandtreatmentcontinues](#) [#gynaecologicalcancer#notallcancerispink](#) [#immunotherapy](#) [#cancer](#) [#fuckcancer](#)

**September 1, 2019**

It's gynaecological cancer awareness month.

Apart from an abnormal period, which I tried to address immediately, I didn't have any other symptoms. I'm not your typical age bracket or risk factor group. I'm not overweight, I wasn't post-menopausal.

Listen to your body. If you feel something is wrong, go to your doctor. If you're not getting answers, drive your medical diagnosis. If it ends up being nothing, at least you got it checked.

Symptoms: - unusually heavy periods and bleeding inbetween your periods  
- an unusual fluid or discharge from your vagina that is watery, bloody or smelly  
- pain in your belly or abdomen  
- trouble going to the toilet to pass urine (wee) or pain when you do go.

[#Repost](#)

. . .

This is not just an older woman's disease! Many of us are diagnosed pre-menopause, in our childbearing years. If you reached puberty, you are at risk! [#givewombcanceravoice](#)

**January 2, 2020**

I've been sick of late. Along with my ongoing 'off-road' journey, been battling a virus and now suspected shingles! My new normal hey? But I have spectacular books I'm excited to devour while I jump over some hoops.

[#holidayreading](#) [#summer2019](#) [#summer2020](#)[#immunitydown](#) [#newnormal](#) [#cancerlyfe](#)

### **November 23, 2020**

A bit about my treatment. I'm on a nationwide cancer trial called Phaedra. It's a IV dosing of an amazing immunotherapy drug called Durvalumab., every three weeks. It's a checkpoint inhibitor drug that uses antibodies to fight the growth of cancer and to remind my T-cells of the types of cancer cells it's to destroy. It's mainly used on patients with advanced cancer. Side effects are very little but a lot of fatigue. Other known side effects are diarrhoea, inflammation of the liver and other major organs, nausea, skin rash, kidney damage, blood clots and type 1 diabetes. With that all said it's rare. This is an incredible work of science and the fact we can live with cancer in this day and age, I find myself very lucky. I'm going to be hitting my 30th cycle soon. That's a long time to be on a trial and rare. Grateful for everyday and grateful for the people in my life and the angels

[#durvalumab](#) [#stage3cancer](#)[#advancedcancer](#) [#cancertreatment](#) [#livingwithcancer](#)[#astrazeneca](#)


### **March 23, 2021**

Back at it. Cycle 34 I think? I'm starting to lose track. Scan results: so so. The tumor increased in size again. Bummer. It's two bad scans and you're off the trial. So technically this should be my last one. But because growth and decrease has been up and down there is no pattern of the treatment not working. So I'm still on durvalumab for the time being. It's a little scary to be honest. I have one more chance to stay on. I feel like I have got strikes on the wall. Fingers crossed no bad scans this year. Send good vibes. [#durvalumab](#)

[#immunotherapy](#) [#petermacallumcancercentre](#)

### **June 16, 2021**

That's what I like to see. Stable disease, no spread

 [#threeyears](#) [#fuckcancer](#) [#cycle36](#) [#scanresults](#)[#endometrialcancer](#) [#stage3](#) [#durvalumab](#)

### **August 9, 2021**

I'm 39 and it's cycle 39! It's not my birthday but it's kind of a celebration I've made it to 39. Three years on and I'm still 'ere. This is my nurse ████████ and I hadn't seen him since my early cycles. Kind of a nice reminder we have so many fab people out there making other people's lives easier.

[#petermac](#) [#stage3](#)[#endometrialcancer](#) [#durvalumab](#) [#cancertrial](#)[#immunotherapy](#) [#gombre](#)

## September 6, 2021

There's a smile under there. Tumor is stable and has shrunk slightly. I'm one of three ladies left on the trial and I'm doing fine 🙌

[#cycle40#durvalumab](#) [#endometrialcancer](#) [#stage3#clearcellcarcinoma](#) [#immunotherapy](#)  
[#itsarollercoaster#kuwaimask](#) [#kuwail](#)

Thank you for all your kind words and good healing energy. I have wonderful mates. The oncologist said I wouldn't be here today without this trial as there is no cure and the likely hood of spread is high. Forever grateful and I'm going to take every moment the savour life. No bullshit and good vibes and energy. X

## April 12, 2022

This is 40. I bloody made it! Spent this time with some of my people on [REDACTED] in [REDACTED]

I'm grateful for the people in my life. I'm also grateful for my medical team at [REDACTED] for getting me into REMISSION after a four year shit show. I'm in a job I love and I'm surrounded by the most inspiring and wonderful souls that enable me to keep going.

Thank you for all the birthday messages I've received.

Here's to the next forty I hope x

## February 21, 2024

Today is my two year remission anniversary. Is it a thing to celebrate? I'm not sure yet. But I'm still here!

I was diagnosed with stage 3C endometrial clear cell cancer 3C in 2018. My oncologist said my chances of survival was minimum on chemo so I was lucky to be the very last person to be placed on a trial drug called Durvalumab. How lucky was that? At 36, I went through a full hysterectomy and IVF to save what I had left of my eggs, I've had hundreds of blood tests, I've gone through 71 cycles of immunotherapy, 40 scans? My veins are still juicy apparently haha

My mind and body as been through the ringer but I've always tried to put it all I perspective. I haven't stopped working (apart from 7 weeks of post surgery recovery) and doing fun things and lucky I haven't had too horrible side effects as other patients (and my heart and love goes to those that haven't had it 'easy'), I have wonderful friends and family and I'm fighting fit. Anyway here's to me 🥳 and more amazing love and gratitude and the smarts of the medical team. My oncologist [REDACTED] and the gorgeous nurses have made going in so much easier.



I'll be on durvalumab for the rest of my life, every three weeks. But how amazing is it to be born in an era where hard working medical and science teams can keep you alive and kicking. As [REDACTED] has said, I wouldn't be speaking with you today.

I'll post symptoms to look out for in my stories. Be advocate for your own health and get a second opinion, surround yourself with good people, protect your energy, smell the roses and the smell of incoming rain...just enjoy being alive! It's ok to be in dark places too but make sure you have the support to come back. X

**Appendix F: Endometrial Cancer Patient Input Sources**

<b>Patient ID</b>	<b>Source</b>	<b>Cancer Type &amp; Stage</b>	<b>Location</b>
<b>PATIENT A</b>	Endometrial Cancer Patient Interview	Stage IV endometrial cancer	██████ Ontario
<b>PATIENT B</b>	Endometrial Cancer Patient Interview	Stage III endometrial cancer	██████ Alberta
<b>PATIENT C</b>	Endometrial Cancer Patient Social Media Account	Stage III endometrial cancer	██████ Australia
<b>PATIENT D</b>	Endometrial Cancer Patient Story Blog	Uterine cancer, stage unknown	██████ ████████ United States
<b>PATIENT E</b>	Endometrial Cancer Patient Story Blog	Synchronous uterine and cervical cancers, stage unknown, NED (Jan 2024)	██████ United States
<b>PATIENT F</b>	Endometrial Cancer Patient Story Blog	Stage IV endometrial cancer	██████ United States

# Clinician Group Input

CADTH Project Number: PC0366-001

Generic Drug Name (Brand Name): durvalumab (Imfinzi), olaparib (Lynparza)

Indication: In combination with carboplatin and paclitaxel is indicated for the first-line treatment of adults with primary advanced or recurrent endometrial cancer who are candidates for systemic therapy, followed by: Imfinzi in combination with olaparib with endometrial cancer that is mismatch repair proficient (pMMR)

Name of Clinician Group: OH (CCO) Gynecologic Cancer Drug Advisory Committee

Author of Submission: Dr. Sarah Ferguson, Dr. Tiffany Zigras, Dr. Julie Nguyen, Dr. Stephen Welch, Dr. Robert Grant, Dr. Julie Ann Francis, Dr. Orit Freedman

## 1. About Your Clinician Group

OH(CCO)'s Drug Advisory Committees provide timely evidence-based clinical and health system guidance on drug-related issues in support of CCO's mandate, including the Provincial Drug Reimbursement Programs (PDRP) and the Systemic Treatment Program.

## 2. Information Gathering

Information was gathered via conference call and emails.

## 3. Current Treatments and Treatment Goals

Currently, there is chemotherapy (usually doublet carbo-Taxol) for pMMR endometrial cancer patients in the upfront setting. In the recurrent setting, the patient must fail one line of platinum-based chemotherapy before being eligible for lenvatinib plus pembrolizumab.

Goals are to prolong life, delay disease progression, reduce symptoms, improve health-related quality of life, and potentially cure disease.

## 4. Treatment Gaps (unmet needs)

- 4.1. Considering the treatment goals in Section 3, please describe goals (needs) that are not being met by currently available treatments.

pMMR patients have an aggressive histologic subtype and don't have a durable response to carboplatin-paclitaxel and have a high rate of recurrence, so we need new treatment options as first line therapy.

## 5. Place in Therapy

5.1. How would the drug under review fit into the current treatment paradigm?

In the pMMR population, this is added to upfront treatment for newly diagnosed measurable stage 3 or stage 4 endometrial cancer, or those with recurrent disease.

5.2. Which patients would be best suited for treatment with the drug under review? Which patients would be least suitable for treatment with the drug under review?

pMMR patients who have newly diagnosed unresectable stage 3 or 4 or those with recurrent disease.

5.3. What outcomes are used to determine whether a patient is responding to treatment in clinical practice? How often should treatment response be assessed?

Combination of imaging and clinical exam as per physician discretion.

5.4. What factors should be considered when deciding to discontinue treatment with the drug under review?

Progression of disease, intolerable toxicity

5.5. What settings are appropriate for treatment with [drug under review]? Is a specialist required to diagnose, treat, and monitor patients who might receive [drug under review]?

In a hospital outpatient systemic therapy unit, under the care of physician who can give systemic therapy.

## 6. Additional Information

## 7. Conflict of Interest Declarations

To maintain the objectivity and credibility of the CADTH drug review programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This conflict of interest declaration is required for participation. Declarations made do not negate or preclude the use of the clinician group input. CADTH may contact your group with further questions, as needed. Please see the [Procedures for CADTH Drug Reimbursement Reviews](#) (section 6.3) for further details.

1. Did you receive help from outside your clinician group to complete this submission? If yes, please detail the help and who provided it.

OH-CCO provided secretariat support to the group.

2. Did you receive help from outside your clinician group to collect or analyze any information used in this submission? If yes, please detail the help and who provided it.

No.

3. List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review. **Please note that this is required for each clinician who contributed to the input — please add more tables as needed (copy and paste). It is preferred for all declarations to be included in a single document.**

### Declaration for Clinician 1

**Name:** Dr. Sarah Ferguson

**Position:** Lead, OH (CCO) Gynecologic Cancer Drug Advisory Committee

**Date:** 01-10-2024

**I hereby certify** that I have the authority to disclose all relevant information with respect to any matter involving this clinician or clinician group with a company, organization, or entity that may place this clinician or clinician group in a real, potential, or perceived conflict of interest situation.

**Table 1: Conflict of Interest Declaration for Clinician 1**

Company	Check appropriate dollar range*			
	\$0 to \$5,000	\$5,001 to \$10,000	\$10,001 to \$50,000	In excess of \$50,000
Add company name				
Add company name				
Add or remove rows as required				

\* Place an X in the appropriate dollar range cells for each company.

### Declaration for Clinician 2

**Name:** Dr. Tiffany Zigras

**Position:** Member, OH (CCO) Gynecologic Cancer Drug Advisory Committee

**Date:** 01-10-2024

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this clinician or clinician group with a company, organization, or entity that may place this clinician or clinician group in a real, potential, or perceived conflict of interest situation.

**Table 2: Conflict of Interest Declaration for Clinician 2**

Company	Check appropriate dollar range*			
	\$0 to \$5,000	\$5,001 to \$10,000	\$10,001 to \$50,000	In excess of \$50,000
Add company name				
Add company name				
Add or remove rows as required				

\* Place an X in the appropriate dollar range cells for each company.

**Declaration for Clinician 3**

Name: Dr. Julie Nguyen

Position: Member, OH (CCO) Gynecologic Cancer Drug Advisory Committee

Date: 01-10-2024

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this clinician or clinician group with a company, organization, or entity that may place this clinician or clinician group in a real, potential, or perceived conflict of interest situation.

**Table 3: Conflict of Interest Declaration for Clinician 3**

Company	Check appropriate dollar range*			
	\$0 to \$5,000	\$5,001 to \$10,000	\$10,001 to \$50,000	In excess of \$50,000
Add company name				
Add company name				

Add or remove rows as required				
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\* Place an X in the appropriate dollar range cells for each company.

**Declaration for Clinician 4**

Name: Dr. Stephen Welch

Position: Member, OH (CCO) Gynecologic Cancer Drug Advisory Committee

Date: 01-10-2024

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this clinician or clinician group with a company, organization, or entity that may place this clinician or clinician group in a real, potential, or perceived conflict of interest situation.

**Table 4: Conflict of Interest Declaration for Clinician 4**

Company	Check appropriate dollar range*			
	\$0 to \$5,000	\$5,001 to \$10,000	\$10,001 to \$50,000	In excess of \$50,000
AstraZeneca	X			
Add company name				
Add or remove rows as required				

\* Place an X in the appropriate dollar range cells for each company.

**Declaration for Clinician 5**

Name: Dr. Robert Grant

Position: Member, OH (CCO) Gynecologic Cancer Drug Advisory Committee

Date: 01-10-2024

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this clinician or clinician group with a company, organization, or entity that may place this clinician or clinician group in a real, potential, or perceived conflict of interest situation.

**Table 5: Conflict of Interest Declaration for Clinician 5**

Company	Check appropriate dollar range*			
	\$0 to \$5,000	\$5,001 to \$10,000	\$10,001 to \$50,000	In excess of \$50,000
AstraZeneca	X			
Add company name				
Add or remove rows as required				

\* Place an X in the appropriate dollar range cells for each company.

**Declaration for Clinician 6**

Name: Dr. Julie Ann Francis

Position: Member, OH (CCO) Gynecologic Cancer Drug Advisory Committee

Date: 01-10-2024

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this clinician or clinician group with a company, organization, or entity that may place this clinician or clinician group in a real, potential, or perceived conflict of interest situation.

**Table 5: Conflict of Interest Declaration for Clinician 6**

Company	Check appropriate dollar range*			
	\$0 to \$5,000	\$5,001 to \$10,000	\$10,001 to \$50,000	In excess of \$50,000
Add company name				
Add company name				
Add or remove rows as required				



\* Place an X in the appropriate dollar range cells for each company.

### Declaration for Clinician 7

Name: Dr. Orit Freedman

Position: Member, OH (CCO) Gynecologic Cancer Drug Advisory Committee

Date: 01-10-2024

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this clinician or clinician group with a company, organization, or entity that may place this clinician or clinician group in a real, potential, or perceived conflict of interest situation.

**Table 5: Conflict of Interest Declaration for Clinician 7**

Company	Check appropriate dollar range*			
	\$0 to \$5,000	\$5,001 to \$10,000	\$10,001 to \$50,000	In excess of \$50,000
Add company name				
Add company name				
Add or remove rows as required				

\* Place an X in the appropriate dollar range cells for each company.